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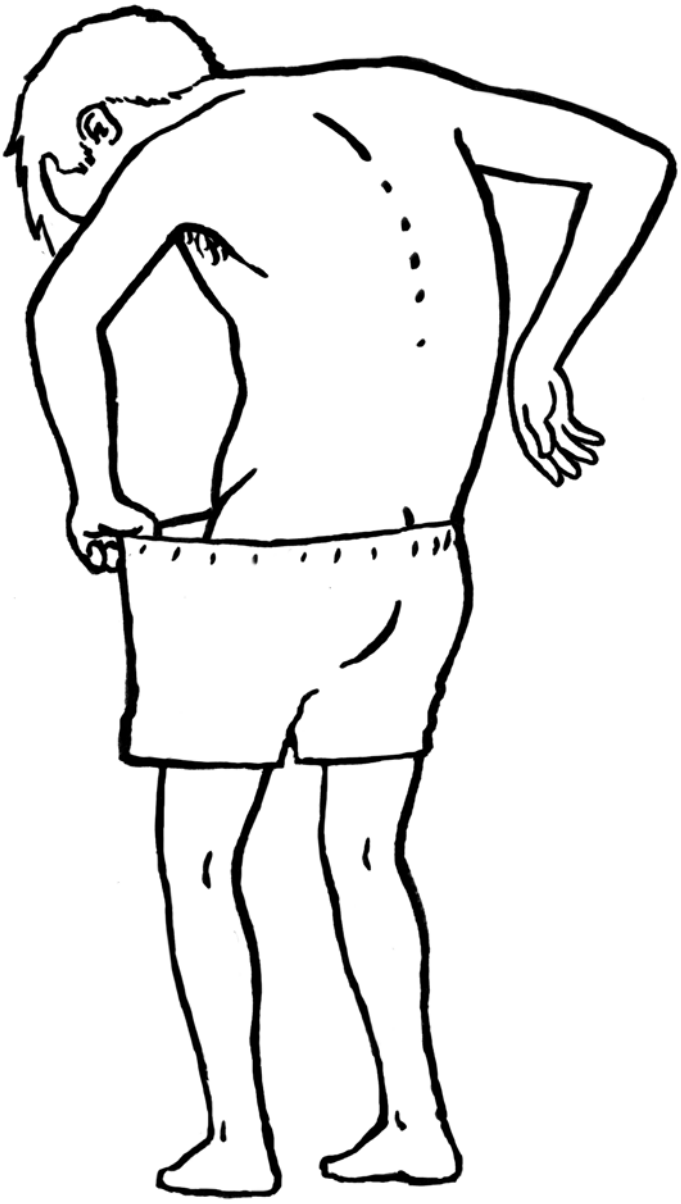

Jeroen Dewinter

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Sexuality in adolescent boys with Autism Spectrum Disorder

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INTRODUCTION

Sexuality is an important developmental task during adolescence, boosted by hormonal changes at the start of puberty (Fortenberry, 2013a; Moore & Rosenthal, 2006). In the 1980's, (grand)parents and professionals (Torisky & Torisky, 1985) still discussed whether or not sexuality was an issue for children and adolescents with Autism Spectrum Disorders (ASD). Over the following three decades, popular and scientific literature on ASD repeatedly suggested a relation between ASD and atypical sexual development and functioning (Bertilsdotter Rosqvist, 2014; Kellaher, 2015). Not only was asexuality linked to ASD, also a lack of sexual knowledge and experience, a delay in sexual development, a high prevalence of Lesbian, Gay, Bisexual, and Transgender people (LGBT), fetishistic arousal patterns, and proneness to sexually inappropriate behaviours and offending (Kellaher, 2015). Although sexuality development gains momentum in adolescence, research on sexual functioning in adolescents with ASD is scant. A better understanding of early sexual functioning could offer cues to support healthy sexual development and prevent problems related to sexuality and relationships.

This thesis aimed to add to the knowledge on sexual development in adolescents with ASD. The focus was on adolescent boys due to the higher prevalence of ASD in boys (2-4:1 male-female ratio (Levy, Mandell, & Schultz, 2009)), the differences in sexual development between boys and girls, and the need to study homogeneous samples. In the course of this study, a mixed methods approach (Creswell & Plano Clark, 2011) was adapted because of the expectation that the combination of quantitative and qualitative methodology would result in a better understanding of sexuality in the participant group. In the quantitative part, the focus lay on the prevalence of common sexual behaviours, feelings and attitudes in boys with ASD compared to typically developing peers in two moments during their development. This quantitative study aimed to offer insight into sexual functioning in adolescent boys with ASD. Parent and self-reported experiences were compared to explore parental awareness of the sexual experience of their children. The qualitative study, based on Interpretative Phenomenological Analysis (IPA; Smith, Flowers, & Larkin, 2009), a methodology with phenomenological, hermeneutic and ideographic theoretical roots, aimed to explore how adolescent boys with ASD experience sexuality and give meaning to it. In the next sections, theoretical considerations relating to sexuality and sexual development in ASD are briefly discussed. Afterwards, the design of this study and the outline of the thesis will be described.

Autism Spectrum Disorders

Characteristics

In the 1940's, Hans Asperger and Leo Kanner both described boys with specific social (isolation, difficulties to make and maintain contact), and behavioural (resistance to change, motor

problems) features (Volkmar, Reichow, Westphal, & Mandell, 2014). Since then, attention to autism grew steadily. In 1980, 'infantile autism' was included for the first time in the third version of the Diagnostic and Statistical Manual (DSM) of the American Psychiatric Association (APA) (Volkmar & McPartland, 2014). At the start of this study, clinicians and researchers used the fourth, text revised version of DSM (APA, 2000). In research and clinical practice, ASD refer to Autistic Disorder, Asperger's Disorder and Pervasive Developmental Disorder, not otherwise specified (PDD-NOS) (Levy et al., 2009) - three subtypes within the category of Pervasive Developmental Disorders in DSM-IV-TR. ASD are characterised by features on the social (difficulties developing friendships, lack of spontaneous sharing of interests, limited social reciprocity) and communicative (difficulties to start and maintain reciprocal interaction, stereotyped and repetitive use of language) domain, and by stereotyped, repetitive behaviours and interests (preoccupations with specific interests, holding on to non-functional routines) (APA, 2000; Levy et al., 2009; Wing, 1993). These characteristics are present in early childhood and remain into adulthood but may not be always visible or impairing (Howlin, Goode, Hutton, & Rutter, 2004; Woolfenden, Sarkozy, Ridley, & Williams, 2012). In contrast to Autistic Disorder, children with Asperger's disorder develop language at an early age and have average or above average intelligence (Baron-Cohen, 2009). PDD-NOS is a heterogenic category (Volkmar & McPartland, 2014), used when people do not adhere to all criteria of both former classifications' criteria. During the time this study was conducted, the fifth version of the DSM was published (APA, 2013). In this version, Pervasive Developmental Disorders are merged into one classification 'ASD'. In a distinct category, the 'social communication disorder' was added, although this disorder resembles PDD-NOS (Volkmar & McPartland, 2014). Research has indicated that a substantial number of children and adolescents with Asperger's syndrome, with Autistic disorder and higher intelligence levels, and with PDD-NOS will not meet the more stringent DSM 5 criteria (Smith, Reichow, & Volkmar, 2015; Young & Rodi, 2013). The actual impact of the implementation of DSM 5 on research and clinical practice still has to become clear. This thesis is based on DSM-IV-TR (APA, 2000) criteria since these were the most widely used in the Netherlands at the time of this thesis.

Comorbid conditions

Comorbid conditions are common in children with ASD, including intellectual disabilities (40-80%), psychiatric disorders (up to 70% (Simonoff et al., 2008): anxiety, ADHD, ODD/CD, depression), and neurological conditions (epilepsy in 20%).

Prevalence

Based on recent studies, a best estimate about the prevalence of ASD lies around .66%, meaning that 1 in 152 children has ASD (Presmanes Hill, Zuckerman, & Fombonne, 2014),

although estimations in school-aged children run up to 2% (Bölte, 2014). The prevalence rates are lower when more stringent (e.g. autistic disorder compared to PDD-NOS) diagnostic criteria were applied (Baird et al., 2006; Levy et al., 2009). ASD occurs two to four times more in males compared to females.

Aetiology

There is consensus that genetic influences play an important role in the genesis of ASD (Bölte, 2014), however research on aetiology is still on-going. Generally accepted is that multiple genetic factors, in interaction with environmental factors, influence brain development (Levy et al., 2009) and information processing resulting in ASD features. In probably less than 10% of cases, ASD is part of a known genetic syndrome (Rutter & Thapar, 2014). Different theories on information processing characteristics relating to ASD try to explain the social, communicative and behavioural features in ASD, e.g. Theory of Mind, systemising-empathising, executive functioning difficulties and central coherence (Baron-Cohen, 2009). Although none of the existing theories can explain all ASD characteristics, they do help to understand ASD-related behaviours.

Sexuality and sexual development

An expert group of the World Health Organisation defined sexuality as follows:

> 'Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles, and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors' (WHO, 2006, p. 5).

Research on sexuality in adolescents was, until the beginning of the 21st century, mainly focused on negative aspects, such as teenage and unwanted pregnancies, sexually transmitted infections, condom use, and sexual offending (Tolman & McClelland, 2011). Since then, sexuality has been, relatively generally, seen as a normative part of adolescent development, i.e. as a normal and expected aspect of human development. Theoretical frameworks behind sexuality research are diverse. Essentialism and social constructionism respectively stress the importance of biological influences (e.g. the role of genetics, hormones, anatomy) versus cultural influences (e.g. the role of language and discourse, the influence of the context) in sexual development. As in many other scientific domains related to human functioning, an integrative, bio-psycho-social perspective has been proposed. However,

most theoretical frameworks related to adolescent sexuality have their own emphasis on the role of biology and context (Moore & Rosenthal, 2006; Tolman & Diamond, 2014b). A combination of research frameworks and methods is probably necessary to add insight into adolescent sexuality. There has been a great deal of attention to the prevalence and age of onset of different sexual behaviours (Fortenberry, 2013a), though in-depth research into other aspects of adolescent sexuality, such as identity and desire, remains limited (Diamond & Savin-Williams, 2009).

Two concepts are central in this thesis. First, normative sexual development (Tolman & McClelland, 2011) refers to the fact that sexuality is an inherent part of adolescent development and, thus, a developmental task for adolescents. Normative behaviours are common, appropriate, and expected regarding age or developmental level (O'Sullivan & Thompson, 2014). Second, sexual health (Fortenberry, 2013; WHO, 2006) is 'a state of (...) well-being in relation to sexuality' (WHO, 2006, p. 5) and includes the presence of positive experiences (pleasure, respect, safety, rights) and the absence of negative aspects (disease, coercion, discrimination).

Sexuality and ASD

The possible influence of ASD characteristics on sexual and relationship development has been discussed by different authors (e.g. Attwood, Hénault, & Dubin, 2014; Hellemans, Colson, Verbraeken, Vermeiren, & Deboutte, 2007; Hénault & Attwood, 2006; Koller, 2000). First, ASD-features (social and communication impairments, stereotyped and repetitive interests and behaviours) can directly interfere with solo- and partnered sexual behaviours. Exemplary, this interference can find expression in sexual behaviours in public, unpremeditated sexual harassment, sexual preoccupations, or specific sensory sexuality related interest. Limited social skills might also impede the development of romantic relationships and the opportunity to enjoy sexuality with a partner, which could lead to frustration. Second, the information processing and communication deficits related to ASD (e.g. literal interpretation of language, need for concrete instruction) can influence how adolescents process direct and indirect information related to sexuality and relationships. Examples here are the (mis) interpretation of sex education programmes and communication related to sexuality, the way information on the internet is interpreted, and how behaviours of peers are understood. Third, the organisation of care, education, treatment, and support for children, adolescents, and adults with ASD can have an influence on sexual development and functioning. Different scripts could be at stake: youth in residential institutions might have limited access to other people (male/female), schools and institutions can choose to offer, or not, sexuality education, and professionals can initiate, or not, discussions on sexuality. Recent research also suggested that psychopharmacological treatments can influence sexual functioning in

adolescents with ASD (Roke, Buitelaar, Boot, Tenback, & van Harten, 2012). Fourth, societal views on sexuality education, sexual rights in people with disabilities, and tolerance towards atypical sexual behaviours can influence how parents, educators, and professionals deal with sexuality in adolescents with ASD. Last, all aspects described above might strengthen or contradict each other (e.g. parental versus institutional attitudes towards sexuality, traditional heteronormative sexuality education versus internet pornography). All in all, the relation between ASD and sexuality development in adolescents with ASD seems complex.

Aims of this thesis

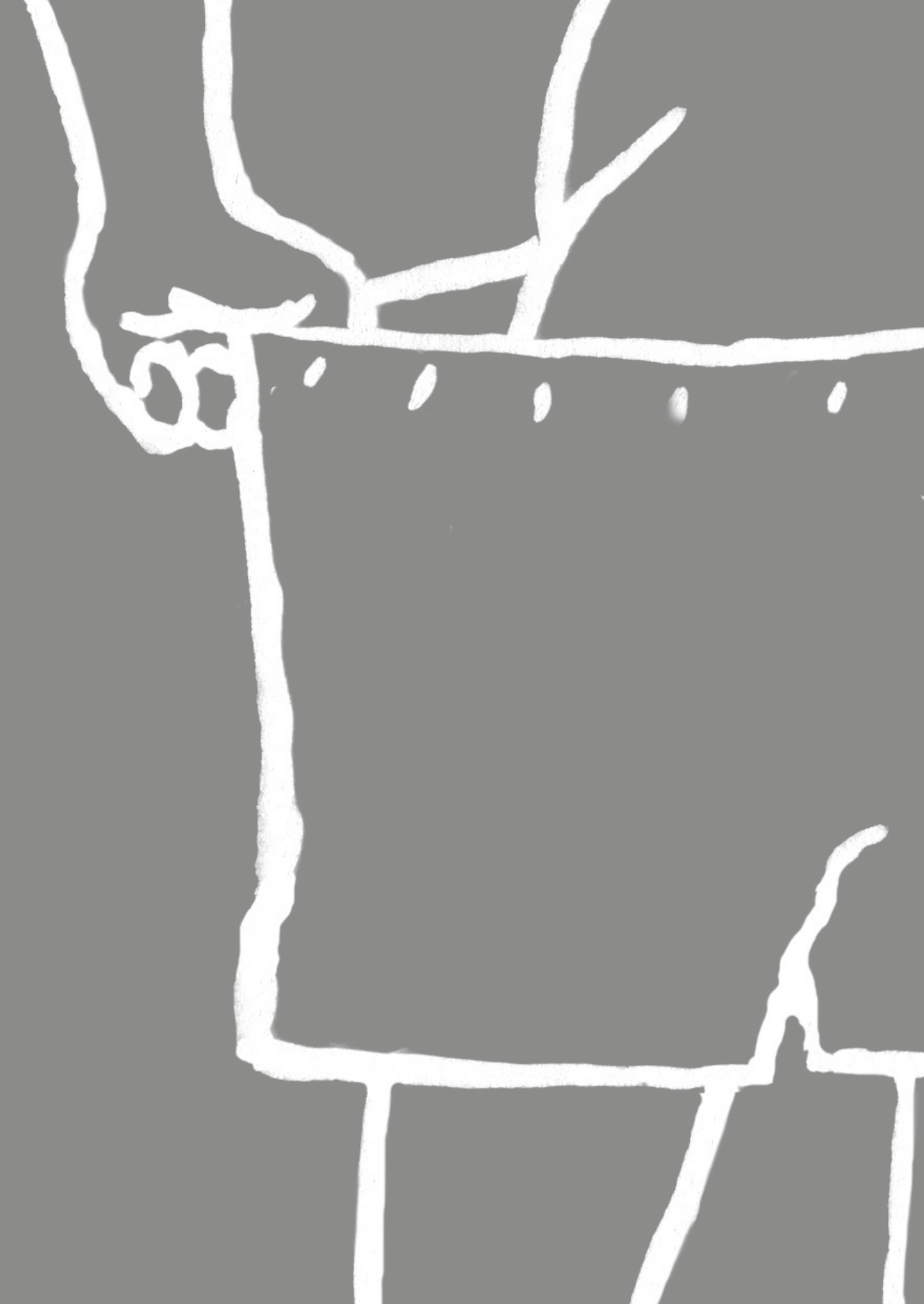
This study aimed to explore sexual development in high functioning adolescent boys with ASD and had four main goals. The first objective was to review the existing research on ASD and sexuality. The second aim was to compare self-reported sexual behaviours in boys with ASD compared to boys in the general population. Third, self- and parent-reports on the adolescents' sexual behaviours were compared. The fourth goal was to gain insight into how boys with ASD experience their sexuality.

Study design and thesis outline

A convergent parallel mixed methods design (Creswell & Plano Clark, 2011) was applied to explore sexual functioning in this thesis. In this type of study-design, qualitative and quantitative data are collected and analysed separately. The results of both methods are merged in the final conclusion. Data were gathered in adolescent boys with ASD. Participants in this study were Dutch and Belgian boys diagnosed with Autistic Disorder or Asperger's Disorder (APA, 2000) between the ages of 15 and 18 at the time of recruitment. All participants were high-functioning (Bölte, 2014): they scored in the below average range or higher on a standardised intelligence measure (Full Scale IQ>70). Florid psychotic symptoms were the only reason for exclusion. Boys with ASD completed the 'Sex under the age of 25 II' questionnaire (de Graaf, Kruijer, van Acker, & Meijer, 2012) on two occasions: 50 boys in 2012-2013, and 30 of the original group at follow-up in 2014. Comparison of these data with the results of a matched control group aimed to test the influence of having ASD on lifetime sexual experience, sexual interest, opinions, attraction, and experience with sex offending in boys during adolescence and emerging adulthood. Parents of 43 boys in the original participant group completed a questionnaire on the sexual experience of their sons. Finally, for the qualitative study, eight boys with ASD, out of the original sample, participated in a semi-structured interview.

In Chapter 1, the scientific research on ASD and sexuality, published between 1980 and October 2012 was reviewed, using the concept of normative sexual development and sexual health as an organising framework. In Chapter 2 the lifetime sexual experiences and sexual

attitudes of the boys, ages 15 to 18, with ASD (*N*=50) were compared to those of a matched general population control group (*N*=90). Chapter 3 explored the agreement between self- and parent-reports (*N*=43 parent-adolescent dyads) on the adolescents' experience with common solo- and partnered sexual behaviours. Chapter 4 described the lifetime experience with common solo and partnered sexual behaviours of the boys with ASD (*N*=30) at follow-up, two years after the initial assessment, compared to those of a matched control group (*N*=60). Additional information on the context and evaluation of the partnered experiences was explored. Chapter 5 reported on the IPA (Smith et al., 2009) of semi-structured interviews conducted in eight boys of the original ASD-group, in order to gain insight into how they experience their sexuality and give meaning to this. The Summary and general discussion integrated the results of the different studies and reflected on the meaning of the results relating to the original framework of sexual health and sexuality as a normative part of adolescent development. The strengths and limitations of the study and the directions for future research were discussed. Finally, the implications of this study's results for education in families, institutions, and schools, and for assessment and treatment in mental health care were discussed.



CHAPTER 1

Autism and normative sexual development: a narrative review

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ABSTRACT

Aims and objectives

To explore the existing knowledge on sexuality and autism spectrum disorders. To this end, the concept of normative sexual development was used as an organising framework.

Background

Sexual health can be seen as a developmental task for all children, adolescents, and adults. Core autism features are related with skills central to sexual development and functioning. More insight in sexual development in people with autism is relevant for education, support, and interventions by parents and professionals in somatic and mental health care.

Method

A comprehensive search of scientific online databases and reference lists was conducted. Publications based on qualitative and quantitative research, including case studies, were selected.

Results

Fifty-five articles and reports were selected and discussed. Information was grouped according to three domains: sexual behaviour, sexual selfhood, and sexual socialization.

Conclusion

Sexual development is a part of life for people with autism of all developmental levels and is generally understudied in this population. Most information was available on behavioural aspects and experiences of socializing agents, such as parents and professionals. Developmental processes and the relation between sexual behaviour, selfhood, and socialization remained unclear.

Relevance to clinical practice

Nurses working in schools, institutions and in general health care support children, adolescents and adults with autism, and advice their families, teachers, other educators and caregivers on sexuality issues. They can have an important role in daily assessment and support of this developmental domain by actively inquiring about the different aspects of sexual development and by offering information. Our findings offer an overview on the existing knowledge and support the idea that sexual development is normative for people with autism just as for anybody else.

Keywords: Autism; Asperger's disorder; sexual development; sexual health; review

What does this paper contribute to the wider global clinical community?

This article offers:

- An up-to-date review of scientific knowledge on sexuality in people with Autism Spectrum Disorders
- An integration of knowledge related to sexual behaviour, sexual selfhood and sexual socialization in people with Autism Spectrum Disorders and their contexts
- Points for attention related to sexual health for nurses and other professionals working with people with Autism Spectrum Disorders

INTRODUCTION

Impairments in social interaction, communication and limited, repetitive and stereotyped patterns of behaviour, interests, and activities (APA, 2000) are the core features of Autism Spectrum Disorders (ASDs). Skills on these domains are important for sexual development and sexual health. There is a growing consensus on the importance of thinking about sexuality and sexual health as a normative and positive aspect of child and adolescent development (SIECUS, 2004; Tolman & McClelland, 2011). This necessitates understanding of the interaction between ASDs and the developmental domain of sexuality. The potentially positive role of sexuality in development and daily functioning, and the importance for caregivers and society to support this, has been stressed (WHO, 2006). In 1985, however, a discussion in the parent section of an autism journal stated that "… sex is not for the majority of autistic people…" (Torisky & Torisky, 1985). This led to an extensive discussion on sexuality and the need for sex education in people with autism spectrum disorders.

In this article, research publications on sexuality and ASDs are reviewed. The framework of sexual health and normative sexual development by Tolman and McClelland (2011) is used. Normative sexual development indicates sexual maturation and physical growth as facts of life that are to be integrated in daily functioning so that these do not hamper an individual's well-being or that of others. Sexual health (WHO, 2006) can be seen as an outcome of a positive sexual development, that is, growing up to be a healthy sexual adult (SIECUS 2004). Tolman and McClelland (2011) discerned three domains in their review of literature on normative sexuality development: (1) sexual behaviour - the behavioural repertoire related to sexuality, solitary or in relation to others (2) sexual selfhood - the internal development of people including knowledge, attitudes, identity and ideas on the self as a sexual being, as a partner in a relationship, etc. and (3) sexual socialization - the different contexts (home and parents, peers, school, partners, internet,…) in which people learn about relationships and sexuality and in which they experience sexuality.

Aims

We undertook this review of research publications in order to describe knowledge related to sexual health in people with an ASD while distinguishing between sexual behaviours, sexual selfhood, and sexual socialization.

Method

A computerised search was conducted in the following databases: Web of Science, PubMed, Psych Info, ERIC). Key words used were: ' sociosexual*', psychosexual*, sexual*, autis*, Asperger*. All abstracts were screened and empirical studies related to sexual development and functioning were included. Studies on the screening of autism symptoms in specific

populations (e.g. juvenile offenders) were excluded. Also excluded were: review and discursive articles, descriptions of test construction and intervention development, book reviews, studies on the influence of vasopressin and oxytocin, legal cases, and articles on facilitated communication in the disclosure of sexual abuse. Only English publications were selected, covering the period 1980 till October 2012. Reference lists were checked for additional relevant articles. Both quantitative and qualitative studies, including case reports on sexuality (behaviour, selfhood and socialization) in people with an ASD were included.

RESULTS

First, the selected studies and their characteristics are briefly discussed (methods used, participants – See Tables 1-2 for an extensive overview). Subsequently, the information from the studies was grouped according to domains described above: sexual behaviour, sexual selfhood, and sexual socialization.

Number of studies

Twenty-six empirical studies and 29 case reports were selected. Two articles (Konstantareas & Lunsky, 1997; Lunsky & Konstantareas, 1998) reported on the same study, so one was excluded. An unpublished report of Haracopos & Pedersen and an article published as an appendix of a book (Hénault & Attwood 2006) were included in these 26 articles, because of their relevance and the fact they were often referred to in other publications

Research methods used

Six studies only used qualitative methods (Ballan, 2012; Bekirogullari, Gulsen, & Soyturk, 2011; Gray, 1994; Hatton & Tector, 2010; Nichols & Blakeley-Smith, 2009; Sperry & Mesibov, 2005). Three of these qualitative studies concerned parental experiences and concerns (Ballan, 2012; Gray, 1994; Nichols & Blakeley-Smith, 2009) or that of teachers and other professionals (Bekirogullari et al., 2011). One quantitative study was based on examination of case files (Lester, White, King, & Drive, 2011; Mandell, Walrath, Manteuffel, Sgro, & Pinto-Martin, 2005). In the remaining studies (*n*=25) semi-structured interviews and questionnaires were used for data gathering (see table 1-2).

Subjects under study

Seventeen studies focussed on high-functioning people with an ASD of different age groups. Nine studies reported about children and adolescents (<age 21) ('t Hart-Kerkhoffs et al., 2009; de Vries, Noens, Cohen-Kettenis, van Berckelaer-Onnes, & Doreleijers, 2010; Haracopos & Pedersen, n.d.; Hellemans et al., 2007; Kalyva, 2010; Stokes & Kaur, 2005; Stokes, Newton, & Kaur, 2007).

Table 1. Studies examining sexual functioning and socialization in individuals with Autism Spectrum Disorders

Author	Focus	Method	*N*
(Balfe & Tantam 2010)	Living, employment and psycho-social situation	Questionnaire (quantitative method (Quant)) Self-report	42
(Ballan 2011)	Content of communication about sexuality between parents and children	Semi-structured interview (qualitative method (Qual)) Parent-report	18 parents of 20 children with Autism Spectrum Disorder (ASD)
(Bedard et al. 2010)	Sexual orientation and gender identity	Questionnaires (quant) Self-report	32
(Bekirogullari et al. 2011)	Information level and attitudes of professionals offering sex-education	Semi-structured interviews (qual) Teacher-report	30 special education teachers and 30 educational psychologists
(Byers et al. 2012)	Factors associated with sexual well-being in people with HFA/ AS	Questionnaires (quant) Self-report	141
(Gilmour et al. 2012)	Sexual attitudes and behaviours of adults with an ASD	Online survey (quant) Self-report	82
(Gray 1994)	Coping stresses and strategies in parents of children with autism	Survey (quant) Interviews (qual) Parent-report	172 parents 33 parents
(Haracopos & Pedersen 1992)	Sexual behaviour in people with autism, experience of staff and assessment of sexual behaviour	Questionnaires filled out by staff	81 people with an ASD
(Hatton & Tector 2010)	Experiences with sex-education	Questionnaires In-depth interviews (qual) Self-report	12 4
(Hellemans et al. 2007)	Sexual knowledge and behaviours of adolescents HFA boys	Semi-structured interviews of caregivers (quant)	24
(Hellemans et al. 2010)	Sexual knowledge and behaviours of adolescents boys with autism and mental retardation (MR) and boys with mental retardation	Semi-structured interviews of care-givers (quant)	20 19
(Hénault & Attwood 2006)	Sexual profile of people with ASD's	Questionnaire Self-report	28
(Kalyva 2010)	Teachers perceptions of sexual behaviours of pupils with ASD's	Questionnaire filled out by teachers (quant)	56 children 20 children
(Konstantareas & Lunsky 1997)	Sexual interest, knowledge, attitudes and behaviours	Questionnaire and interview (quant) Self-report	15 16

Diagnosis	Sex	Age	Intelligence	Control-group
High Functioning Autism (HFA) or Asperger Syndrome (AS)	37 male, 5 female	*M* = 26, 21, *SD* = 11,9, range 13-64	IQ>70	no
ASD	Parents: 16 female, 3 male children: 19 male, 1 female	Children between age 6 and 13	Unknown	no
Developmental disabilities 2 ASD	16 male, 16 female 1 male, 1 female	*M* = 39 years, range 20- 64	Borderline intelligence to high moderate level of developmental disability	no
n/a	2*15 males and 2*15 females			no
Professional diagnosis of ASDs (Autism Quotient (AQ)>26)	56 male, 85 female	*M* = 39.6, range 21-73	High-functioning, 60% had completed an under-graduate or graduate degree	no
Self-reported ASD, confirmed by AQ	55 female, 17 male	*M* = 28.9 years, *SD* = 9.3	Unknown	282 people in general population/ Students
Children with ASD	Unknown	Unknown	Unknown	no
ASD: 22 high functioning, 42 moderate functioning, 17 low functioning	57 male, 24 women	Range 16-40	25 with good language, 29 fairly well spoken language, 27 very little or no spoken language	no
ASD AS and HFA	Unknown	Unknown	Unknown	no
Autistic disorder: 14 AS: 6 Pervasive Developmental Disorder – Not otherwise specified (PDD NOS): 4	All male	*M* = 17 years, range 15–21	IQ *M* = 90, range 71-113	no
ASD and MRR	12 female, 5 male; 6 female, 12 male;	*M* = 35 years, range 27–52; *M* = 38 years, range 21–50	*M* IQ = 67.95, *SD* = 7.22, range: 54–78; *M* IQ = 67.89, *SD* = 6.97, range: 55–78	Autism vs. non-autism
21 AS 5 HFA 2 PDD confirmed with AQ	19 male 9 female 3 trans-sexual (2 F, 1M)	*M* = 34, range 18-64	Unknown	50 controls
Low functioning autism (LFA) HFA or AS	38 male 18 female 16 male 4 female	*M* = 10 years and 7 months, range 7-14	IQ<70 Average IQ	No
ASD Developmental delay (DD)	9 male, 6 female 8 male, 8 female	*M* = 28.1, *SD* = 7.7, range 16-46	2/3 mild MR 1/3 moderate-severe MR	ASD vs. DD

Table 1. Continued

Author	Focus	Method	*N*
(Lunsky & Konstantareas 1998)	Sociosexual attitudes of people with developmental disabilities	Questionnaire and interview (quant) Self-report	15 16
(Mandell et al. 2005)	Abuse in children with autism in the community	Existing data-file (quant)	156 children with autism
(Mehtar & Mukaddes 2011)	Post Traumatic Stress Disorder in children with ASD	Assessment, questionnaires and interview (quant) Parent- and self-report	69 children and adolescents
(Mehzabin & Stokes 2011)	Sex-education, socio-sexual knowledge, behaviours and worries in people with HFA	Questionnaire (quant) Self-report	21 people with HFA 39 typically developing (TD)
(Nichols & Blakeley-Smith 2009)	Concerns and needs of parents regarding sex-education of their children with an ASD and evaluation of an intervention	Focus-groups (qual) Questionnaire pre/post-test (quant)	21 parents of youth with an ASD 10 parents
(Ousley & Mesibov 1991)	Sexual knowledge and interests in people with HFA and mental retardation	Questionnaire (quant) Self-report	21 HFA 20 mental retardation (MR)
(Ruble & Dalrymple 1993)	Parental views on sexual awareness, education and behaviour	Questionnaire (quant) Parent-report	100
(Sperry & Mesibov 2005)	Perceptions of social challenges by adults with autism	Focus group (qual)	18
(Stauder et al. 2011)	Masculinization of gender role behaviour in people with autism	Questionnaires (quant) Self-report	25 25 controls Age & sex-matched
(Stokes & Kaur 2005)	Parental views on sexual knowledge, education and behaviour	Questionnaire (quant) Parent-report	23 HFA 50 controls
(Stokes et al. 2007)	Parental views on social and romantic functioning in people with autism	Questionnaire (quant) Parent-report	25 ASD 38 controls
(Van Son-Schoones & Van Bilsen 1995)	Sexual development of autistic ons	Questionnaire (qual) Interviews (qual)	37 parent-couples 14 parents 4 health care workers 4 ASD men
(Van Bourgondien et al. 1997)	Sexual behaviour of people with autism living in group homes	Questionnaire on sexual behaviour and group policy filled out by professional (quant)	89

Quant = quantitative method, Qual = Qualitative method, M = Mean, sd = Standard deviation, SE = standard Error, HFA = High Functioning Autism, AS = Asperger Disorder, AD = Autistic Disorder, ASD = Autism Spectrum Disorder, AQ = Autism Quotient, CARS = Childhood Autism Rating Scale, MR = mental retardation

Diagnosis	Sex	Age	Intelligence	Control-group
ASD Developmental delay	9 male, 6 female 8 male, 8 female	*M* = 28.1, *SD* = 7.7, range 16-46	2/3 mild MR 1/3 moderate-severe MR	2 control groups: 25 undergraduate students 28 controls
AD AS	108 male 48 female	*M* =11,6, *SD* = 3,8	Unknown	No
59 AD, 5 AS 5 PDD-NOS	53 male 16 female years. On	*M* =11 years 7 months, *SD* = 3 years 3 months, range 6–18	Unknown	n/a
HFA AS	12 males 9 females 15 males 24 females	*M* = 25.3 years, *SD* = 3.6 *M* = 23.4 years, *SD* = 1.9 *M* = 23.7 years, *SD* = 3.1 *M*= 22.6 years, *SD* = 2.1	Unknown	HFA <> TD
11 AD 8 AS 2 PDD-NOS 4 AD 6 AS	13 male, 8 female 5 male, 5 female	*M* = 13, range 8-18 Range 10-14	IQ< 65 = 3 65-84 = 6 85–114 = 7 > 115 = 4 Low average to above average	No
HFA (Childhood Autism Rating Scale (CARS)	11 male 10 female 10 male 10 female	*M* = 27y4m, *SD* = 5,4 *M* = 27y3m, *SD* = 5,9 *M* = 27y11m, *SD* = 5,9 *M* = 27y5m, *SD* = 7,9	*M* IQ = 84,4, SD = 8,1 *M* IQ = 73,9, SD = 15,8 *M* IQ = 56,9, SD = 11,1 *M* IQ = 54,6, SD = 13,4	ASD <> MR
ASD	68 male 32 female	*M* = 19,5, range 9,1-38,9	84% mental retardation	No
ASD	17 male 1 female	*M* = 34, range 22-49	Unknown, Highly educated sample	No
9 AS 8 AD 8 PDD-NOS	16 male 9 female	*M* = 34,81, *SD* = 9,37 *M* = 27,89, *SD* = 10,87	Normal range	ASD<>controls
HFA or AS	17 male 6 female 33 male 17 female	*M* =12,6, *SD* = 1,9 *M* = 13, *SD* = 0,6 *M* = 13,5, *SD* = 1,4 *M* = 13,1, *SD* = 1,5	Unknown	HFA<> controls
3 AD 3 HFA 19 AS	16 male 9 female 32 male 6 female	*M* = 22,21, *SD* = 4,83, range 13-36 *M* = 20,83, *SD* = 4,83, range 13-30	> 70	HFA<> controls
ASD	Unknown	Age 12-30 Age 18-30	Not specified Normally gifted	No
26 mild autism 23 moderate autism 51 severe autism	72 male 17 female	*M* = 28, range 16-59	18 mild MR 22 moderate MR 60 severe MR 33% nonverbal	No

Table 2. Case reports on sexual behaviours in individuals with ASDs

Study	Focus	# cases
(Baron-Cohen 1988)	Relational violence of male towards his 71 year old partner	1 male
(Chan & Saluja 2011)	Sexual inappropriate behaviours since age 11. Change in autism features after Traumatic Brain Injury.	1 male
(Cooper et al. 1993)	Transvestism and history of sexually offensive behaviours	1 male
(Coskun et al. 2009)	Psychopharmacological treatment of excessive masturbation and inappropriate behaviours	10 (8 male, 2 female)
(Coskun et al. 2008)	Psychopharmacological treatment of offensive fetishism in a 13 year old boy with autism	1 male
(Dozier et al. 2011)	Behavioural intervention in a man with an offensive shoe fetish	1 male
(Early et al. 2011)	Behavioural intervention in an adolescent with an offensive preoccupation with female feet	1 male
(Gallucci et al. 2005)	Gender identity problems in a men with Asperger's disorder	1 male
(GriffiShelley 2010)	Treatment of adolescent boy with Asperger's disorder referred because of sexually offensive behaviours and sex addiction	1 male
(Jones & Okere 2008)	Hormonal treatment of hyper sexuality and offensive behaviours	1 male
(Kohn et al. 1998)	Adolescent boy with Asperger's disorder presenting with repeating sexual assault and physical aggression	1 male
(Kraemer et al. 2005)	Assessment of a women with Asperger's disorder and gender identity disorder	1 female
(Landén & Rasmussen 1997)	Girl with autism and transsexuality	1 female
(Lewis 2006)	Psychodynamic treatment of 3 boys with developmental disabilities during adolescence	3 males
(Milton et al. 2002)	Assessment and treatment of a man with Asperger's syndrome, paraphilic and offensive behaviours	1 male
(Mukaddes 2002)	Gender identity problems in 2 boys with autism	2 males
(Müller 2011)	MRI research on amygdalahippocampal lesions in a man with autism convicted for murder. Sadomasochism and hyper sexuality	1 male
(Murrie et al. 2002)	Case studies of forensic patients with Asperger's disorder convicted for different types of crimes (2, 4,5,6 concerning sexual offensive behaviours)	6 males
(Parkes et al. 2009)	Cross-dressing and gender dysphoria in 13 people with learning disabilities	12 males 1 female
(Perera et al. 2003)	Girl with AS and Obsessive Compulsive Disorder (OCD) and gender dysphoria during adolescence	1 female

Diagnosis	Information on development	Age	IQ
Asperger Syndrome (AS)	Yes	21	TIQ 80, VIQ 92, PIQ 69
Autism	Yes	25	TIQ 65
AS	Yes	38	TIQ 54
Autistic Disorder (AD)	No	5,2-16,4 *M* = 12.4, *SD* = 3.58	Unknown
AD	Yes	13	Probably Moderate mental retardation
Autism	Yes	36	Little expressive language
Autism	Yes	16	Normal range
AS Gender Identity Disorder (GID)	Yes	41	Probably normal range
AS	Yes	14 followed till adulthood	VIQ 121 PIQ 86
Autism	No	23	Unknown
AS	Yes	16	IQ 120
AS GID	Yes	35	Verbal intelligence 125
AD	Yes	14	IQ 110
1. Bipolar disorder and Pervasive Development Disorder – Not Otherwise Specified (PDD-NOS) 2. AS 3. Multiple Complex Developmental Disorder (MCDD)	Yes	8 through adolescence and both 10 through adolescence	Unknown
AS	Yes	Early thirties	IQ 80
AD AD	Yes Yes	10 7	IQ 75 IQ 85
AD	Yes	29?	IQ 81, VIQ 76 PIQ 94
AS	Yes	1. 31 2. 27 3. 44 4. 33 5. 22 6. 31	1. Borderline low average range 2. VIQ average, PIQ borderline to mental deficit 3. Above average 4.average 5. Normal range 6. Unknown
1 ASD	No	Unknown	Unknown
AS OCD GID	Yes	Followed from age 9 till 20	Unknown

Table 2. Continued

Study	Focus	# cases
(Ray et al. 2004)	Reflection on sexual development in adolescents with AS and treatment of problems. 4 cases: Tim, Bill (offensive fetish), Will (offensive fetish), Max (traumatized, sexually offensive)	4 males
(Realmuto & Ruble 1999)	Definition of sexual behaviour and problems, illustrated with case-report (deviant sexual arousal, public masturbation)	1 male
(Ritvo et al. 1988)	11 possible parents with autism	2 female 9 male
(Silva et al. 2002)	Case report on serial sexual homicidal behaviour	1 male
(Singh & Coffey 2012)	Case report on a boy with excessive masturbation, gender dysphoria and deviant sexual interest and intrusive sexual thoughts	1 male
(Stefanos et al. 2011)	Psychodynamic treatment of adolescent aimed at addressing sexuality and emotional problems	1 male
(Tateno et al. 2008)	Assessment of 5 year old boy with gender dysphoria	1 male
(Tissot 2009)	School policy on sexuality in their pupils: 6 case reports 1. Public masturbation, 2. Inappropriate touching 3. Distress at menstruation 4. Public undressing and masturbation 5. Homosexual relation 6. Inefficient masturbation technique	5 male (1,2,4,5,6) 1 female (2)
(Williams et al. 1996)	2 children with cross-gender preoccupations (playing with dolls, cross-dressing)	2 males

AS = Asperger Syndrome, AD = Autistic Disorder, GID = Gender Identity Disorder, MCDD = Multiple Complex Developmental Disorder, OCD = obsessive Compulsive Disorder, PDD-NOS = Pervasive developmental Disorder Not Otherwise Specified

In the case reports, 65 people (57 male) are described. Thirty-one reports contain developmental information. Thirty-seven cases were children and adolescents. All report on specific or deviant problems and behaviours (23 gender dysphoria and cross-dressing, seven on fetishism, inappropriate masturbation and offensive behaviours).

Sexual Behaviour

In this section, the findings on observable, behavioural aspects of sexual health are described.

Solitary sexual behaviour

Masturbation was observed in 40 to 77.8% of the men with ASDs (Haracopos & Pedersen, n.d.; Hellemans et al., 2007, 2010; Konstantareas & Lunsky, 1997; Ousley & Mesibov, 1991; Van Bourgondien et al., 1997) and self-reports revealed weekly solitary sexual activity, with higher desire and activity in males than in females (Byers, Nichols, Voyer, & Reilly, 2012). Masturbation frequency reported in females was 20% to 54.2%. Masturbation habits often were unknown

Diagnosis	Information on development	Age	IQ
AS	Yes (limited)	Age 15 Age 17 Age 16,5 Age 14	Unknown
AD	Yes	Young adult	Low average
No formal diagnosis	Limited	Adults	Unknown
Assumed AS	Yes	Adult	Above average to high
PDD-NOS OCD Bipolar disorder-NOS	Yes	16	59
AS	Limited	15	Unknown High school education
AS GID	Yes	Entered at age 5	TIQ 92, VIQ 90 PIQ 96
Autism spectrum disorders	No	1. 11 2. 12,5 3. 12 4. 16 5. Both 19 6.11	Unknown
1. AD 2. AD	Yes	1. 5 2. 3,7	1. 105 2. Developmental delay

to caregivers, which is in line with Haracopos & Pedersen (n.d.) stating that higher functioning people with an ASD are more appropriately private in their sexual behaviour. These observed rates are lower than self-reported rates of typically developing adolescents. In the Netherlands, 93% of boys between age 18 to 20, and 73% of girls reported masturbation (de Graaf et al., 2012). Masturbating techniques were often (29%) instructed by caregivers (Hellemans et al., 2007) and masturbation did not always lead to orgasm (men: 64.3% - 69% of those who masturbated, women: 25% - 46.1%) (Haracopos & Pedersen, n.d.; Van Bourgondien et al., 1997). In the typically developing adolescents age 18 - 20 in the Netherlands, 93% of boys and 77% of girls experienced an orgasm (de Graaf et al., 2012). Hellemans et al. (2007) found compulsive masturbation in 17% of the boys with an ASD in his sample and this behaviour was also described in several case studies (Coskun, Karakoc, Kircelli, & Mukaddes, 2009; Griffin-Shelley, 2010; Singh & Coffey, 2012). It is not clear how compulsivity was defined, although in most case reports it was the public character of masturbation that led to such labelling. Public masturbation, in general, was noted in several studies (Coskun et al., 2009; Dozier, Iwata, & Worsdell, 2011;

Tissot, 2009), although it was reported less frequently in higher functioning people (Haracopos & Pedersen, n.d.; Hellemans et al., 2007). Particular sexual behaviours and interests were found in low frequencies but in several studies: arousal in the presence of certain objects or specific characteristics of people (such as hair or feet) (Hellemans et al., 2007; Van Bourgondien et al., 1997), the use of specific objects (e.g. a belt, hard objects) for masturbation (Haracopos & Pedersen, n.d.; Hellemans et al., 2007, 2010), and deviant interests (e.g. in prepubertal children) (Hellemans et al., 2007; Realmuto & Ruble, 1999). Deviant or unusual sexual behaviours and interests were also described in multiple case studies, such as fetishism (Cooper et al., 1993; Coskun & Mukaddes, 2008; Dozier et al., 2011; Early et al., 2012; Ray et al., 2004) and an interest in young children (Chan & Saluja, 2011; Realmuto & Ruble, 1999).

Sexual interaction and relationships

Despite the social difficulties central in ASDs, a clear interest in romantic and/or sexual dyadic relationships was found in many of the studies of adolescents and adults with an ASD. About half of people with High Functioning Autism (HFA) demonstrated sexual behaviours towards others (Haracopos & Pedersen, n.d., Byers et al. 2012) or talked about their need for being in a relationship (Hellemans et al. 2007). Also, about half of the group of adolescents in the study by Hellemans et al. (2007) was or had been in a romantic and physical relationship. In the group of adults with Asperger Syndrome studied by Hénault and Attwood (2006) 43% of the 28 participants had been in a relationship, and Byers and colleagues (2012) studied sexual well-being of 141 people with an ASD who all were or had been in a romantic relationship.

Information on other sexual behaviours remains scarce. The number of people engaging in kissing varied from 9 to 100% in males and little less in females. Hugging and petting was reported in 0 to around 50%. Experience of mutual masturbation, oral sex, penile-vaginal or anal intercourse, was explored in only a few studies. Hellemans et al. (2007, 2010) studied sexual behaviours of adolescents (age 15 - 21) with an ASD with and without mental retardation (MR). In the HFA group 13% of 24 had had sexual intercourse (vaginal or anal) and another 13% had attempted this. In the group with ASD and MR, two of twenty participants had an experience of mutual masturbation. Of the 21 adults with HFA in the study by Ousley & Mesibov (1991) only one of the 10 females and none of the male participants reported 'to have gone further than hugging and kissing'. Van Bourgondien et al. (1997) found that only one participant in their group of adults (n=89) with an ASD and MR had sexual intercourse (not specified) and four had attempted to (three male, one female). Haracopos and Pedersen (n.d.) found one female that had experienced sexual intercourse, but this was against her will. However, a substantial number of people who were interested in a sexual relationship had no or little experience of one (Haracopos & Pedersen, n.d.; Ousley & Mesibov, 1991). Stokes et al. (2007) looked at parent-reports and found a clear relation between social and romantic functioning.

In adolescents the subjects of their romantic interests were more diverse compared to typically developing controls and more frequently unattainable, with unrealistic infatuations reported (e.g. caregivers, celebrities, etc.) (Haracopos & Pedersen, n.d.; Stokes et al., 2007).

Sexually inappropriate behaviours

Sexually inappropriate behaviours among people with an ASD of all different functional levels have been reported in quite a number of case studies (Baron-Cohen, 1988; Chan & Saluja, 2011; Cooper et al., 1993; Griffin-Shelley, 2010; Kohn, Tarek, Ratzoni, & Apter, 1998; Milton, Duggan, Latham, Egan, & Tantam, 2002; Murrie, Warren, Kristiansson, & Dietz, 2002; Ray et al., 2004; Silva, Ferrari, & Leong, 2002). These varied from solitary behaviours (e.g. public masturbation) to inappropriate romantic behaviours (e.g. unwanted courting) to sexual offenses (e.g. assault and rape). In many cases it was unclear whether the person was aware of the consequences of his/her behaviour. Some authors have developed discussion on what they have termed 'counterfeit deviance' (Gougeon, 2010; Hellemans et al., 2007; Nichols & Blakeley-Smith, 2009): deviant behaviours resulting from a lack of knowledge and support. Stokes and colleagues (2007) found that adolescents and adults in their group with ASDs demonstrated more inappropriate courtship behaviours (inappropriate touching, threatening…) and less appropriate strategies (e.g. asking someone out) compared to controls. Different mechanisms underlying these offensive behaviours have been suggested: a lack of social insight and skills, limited empathy, limited understanding of social information or social awareness, a lack of inhibition and knowledge, but also preoccupations, sensory preferences, reduced emotion recognition, persistent, repetitive and stereotyped behaviours ('t Hart-Kerkhoffs et al., 2009; Haracopos & Pedersen, n.d.; Hellemans et al., 2007; Nichols & Blakeley-Smith, 2009; Stokes et al., 2007). Children who experienced physical and sexual victimisation were also more likely to demonstrate sexual abusive behaviours towards others (Mandell et al., 2005). Thirty-seven case studies reported on offensive behaviours, including developmental information on the subject. These inappropriate behaviours (public masturbation, inappropriate touching, deviant interest) frequently seemed to start early in adolescence.

Sexual selfhood

Next to the visible, behavioural aspects of sexuality, sexual health also refers to mental and emotional aspects.

Sexual interest and orientation

The studies on sexual behaviour revealed an interest in sexuality in the majority of people with an ASD (Byers et al., 2012; Gilmour et al., 2012; Hellemans et al., 2007; Van Son-Schoones & Van Bilsen, 1995), although feelings of asexuality were also reported (Gilmour et al.,

2012). Konstantareas and Lunsky (1997) found, in 15 individuals with ASD and a cognitive impairment, an interest in marrying and having children rather than in sexuality. Hénault and Attwood (2006) found that their adult participants reported that the age of first interest in sexuality was 14 on average. The age of first sexual experiences was 21 on average. In general, sexual interest and desire was higher in men compared to women (Hénault & Attwood, 2006; Ousley & Mesibov, 1991).

In different studies a higher than expected rate of homo- or bisexual interest was found (Byers et al., 2012; Haracopos & Pedersen, n.d.; Hellemans et al., 2007), 12% - 35% compared to 3.1% of boys and 2.4% of girls age 12 to 25 that reported attraction towards a same-sex partner in a recent survey in the Netherlands (de Graaf et al., 2012). Gilmour et al. (2012) found higher scores on a dimensional measure of homosexuality in females in their group with ASDs compared to their control group. Many participants in the study of Hénault and Attwood (2006) reported homosexual fantasies.

Sexual knowledge

Results on sexual knowledge are inconclusive. Comparison of people with and without ASDs, also when matched on intelligence levels, revealed contradicting results, with average knowledge levels in HFA groups (Byers et al., 2012; Gilmour et al., 2012; Hatton & Tector, 2010; Ousley & Mesibov, 1991), and lower scores compared to controls in other studies (Hénault & Attwood, 2006; Konstantareas & Lunsky, 1997; Mehzabin & Stokes, 2011). In their study of HFA adolescent boys, Hellemans et al. (2007) found adequate basic knowledge on self-care and socio-sexual skills, but this was not reflected in the actual behaviour and functioning. In their later study with adolescents (2010) with ASD and MR this adequate theoretical knowledge was confirmed and no problems were seen in the transfer to daily functioning. The authors remarked that the institutions supporting this group had paid attention to training these knowledge and skills.

Worth noticing is that sexual knowledge was operationalized in different ways ranging from basic vocabulary knowledge, broad socio-sexual knowledge, judgments of parents and caregivers on knowledge to more complex knowledge on sexual physiology and behaviour. This may, in part, explain the differences found.

Sexual well-being

Sexual well-being is a broad term including knowledge, attitudes and behaviours towards the self, sexuality and others. This way, it covers aspects of sexual behaviour and selfhood. Two studies concerned sexual functioning and well-being. Byers et al. (2012) included 141 high-functioning people with ASDs who were or had been in a romantic relationship. In the other study (Hénault & Attwood, 2006) 43% of participants had been in a relationship. Both studies found that being in a relationship positively correlated with emotional and

sexual satisfaction. Byers and colleagues (2012) found that people with lower levels of social functioning or communication skills, showed less satisfaction and self-esteem, and higher anxiety in the context of a relationship. No relation was found between ASD symptoms and solitary sexual well-being, based on sexual knowledge, moderate desire, thoughts (1-2 times/week) and activity (1 time/week). Men reported higher desire, thoughts and masturbation while women scored higher on knowledge measures. Hénault and Attwood (2006) used the DSFI (Derogatis Sexual Functioning Inventory) and found, compared to normal controls, a more negative body image, more distress symptoms, and more negative affect. The sexual satisfaction in their group was lower, but general sexual satisfaction was comparable to the normal controls. They found average scores on scales concerning fantasy, sexual desire, and gender roles. The longing for a relationship and sexuality, combined with the absence of it, could be an explanation for the high number of people with ASDs in a community sample (56%) reporting sexual frustration (Balfe & Tantam, 2010).

Finally, of relevance in adolescence are reactions to pubertal bodily changes. Anxiety and distress in reaction to secondary sexual characteristics (physical changes, sexual reactions) were reported by caregivers (Hellemans et al., 2007; Ruble & Dalrymple, 1993) and in case studies.

Gender identity

In nine case reports gender problems (gender dysphoria, gender identity disorder) in people with ASDs were described. There is no systematic research into this phenomenon, only research on ASD symptoms and diagnosis in larger groups of people with gender identity problems. Underlying mechanisms and processes were not studied. Stauder et al. (2011) found less masculinised gender roles in men with an ASD using MMPI-2, compared to the instrument's norm group. Discussion on the differentiation between gender dysphoria and obsessive-compulsive behaviour emerged in different cases. It was unclear which condition was primary and if gender problems could be seen as a separate condition (Gallucci, Hackerman, & Schmidt, 2005; Landén & Rasmussen, 1997; Perera, Gadambanathan, & Weerasiri, 2003).

Sexual socialization

The third domain relevant to sexual development and sexual health is that of education and socialization in different ecological systems (home, school, institution, peers, partners, society). Research on sexuality in adolescents and adults with an ASD has mainly been focused on experiences of socializing agents: parents (views and attitudes, communication and education by parents), professionals in group homes (policies, training of professionals) and in community services. Some studies explored other contexts such as peer contacts, school and media. Victimization will also be discussed below, since this should also be viewed as a contextual influence on sexual development.

Parents as socializing agents

An explorative study on the living situation of a community sample of adolescents and adults with Asperger's disorder showed that most of these individuals lived with their parents, had limited social contacts and a small social demography (Balfe & Tantam 2010). This suggests that parents and professionals remain, for a long time and for a lot of people with autism, important sources of information and support concerning sexuality.

Studies on parental perceptions and attitudes often revealed concerns or problems perceived by parents. Nichols and Blakeley-Smith (2009) report concerns about abuse or sexual exploitation of and by their children. Parents of younger children also worried that behaviours of their children would be seen as having sexual content (Ballan, 2012). In an older and lower functioning group of people, Ruble and Dalrymple (1993) found that parents were concerned that the behaviour of their children would be misunderstood by others as sexually intended on the one hand, and on the other hand that their sexual behaviours would be misinterpreted. A small number of parents reported worries about sex education to nonverbal adolescents and about their sons having a sexual relationship. Parents were concerned about sexual abuse of their children by men. Parents of males had questions on controlling masturbation while parents of girls had questions on the use of contraception. One study reported that concerns seemed to increase with age of the adolescents with ASD but the content of these concerns was not explored (Stokes & Kaur, 2005). In another study the concerns changed from confusion about bodily reactions such as an erection in younger children to broader worries on interpretation of behaviours, the use of contraceptives and condoms, control of masturbation and the need for sex education (Ruble & Dalrymple, 1993). Attitudes and cognitions among parents influenced if sex education was offered: negative expectations about sexual functioning versus the conviction that sexuality was important for children with ASD; worries about preoccupations (e.g. wanting to know everything about sex), persistent behaviours or overgeneralization (e.g. asking everybody questions about sex); the expectancy that their children could have relationships; and opinions about who was responsible for sex education. Despite this, parents of children with ASDs seemed prepared to discuss sexuality with their children with an ASD (Ballan, 2012), especially parents of higher functioning children and adolescents (Ruble & Dalrymple, 1993). Parents reported a strong need to discuss sexuality and sex education with others and specifically with professionals. However, parents reported negative reactions to sexual behaviours, including from professionals, even when behaviours were age appropriate. Spontaneously offering information or informing about sexual development by professionals was lacking (Ballan, 2012; Nichols & Blakeley-Smith, 2009).

Professionals as socializing agents

Van Bourgondien et al. (1997) found that only a minority of professionals working in group homes received formal training in supporting residents in managing their sexual feelings. Haracopos and Pedersen (n.d.) described an open and positive attitude towards sexuality in their residents amongst professionals, but a majority thought a sexual relationship was unrealistic and openness was not reflected in daily support. Teachers also observed sexual behaviour and assessed knowledge of adolescents with ASDs and were concerned about their further development (Kalyva, 2010), but it is not clear if they knew how to handle this. A study among educational psychologists and special education teachers in Cyprus showed a lack of knowledge on sexuality and sex education (Bekirogullari et al., 2011).

Sex education

There is no systematic outcome research on sex education for adolescents with ASDs. Two studies looked at the perception of sex education by adolescents with ASDs. A qualitative study with four participants (Hatton & Tector, 2010) revealed the need for more insight into their own ASD symptoms and functioning, and basic insight into social and romantic relationships. These participants were thought to have enough 'technical' knowledge, but lacked the insight to use this well. Mehzabin and Stokes (2011) compared self-report data on sex education of HFA adolescents with typically developing adolescents and found that the HFA adolescents reported lower levels of sex education and knowledge. There are no extensive studies on the effect of internet use on sexual development of adolescents with an ASD. In one study was assumed that younger people would benefit from the availability of information on the internet and would score higher on sexual well-being measures, but this was not confirmed (Byers et al., 2012).

Treatment and interventions

No effects studies on interventions in case of sexual problems were found. Case reports described behavioural interventions (applied behavioural analysis, social stories, visualization, explicit teaching, rewarding) and their positive effects. In some cases a behavioural approach was used to teach adolescents with autism acceptable sexual behaviours, in other cases sexuality was inhibited or primarily treated as a medical disorder.

Sexual victimization

The study on victimization in children with ASDs by Mandell et al. (2005) revealed a prevalence of 12.2% of sexual abuse and 4.4% of combined sexual and physical abuse in a community-based sample of children with ASD in the USA. Afterwards, these children demonstrated a significant higher level of sexually acting out and sexually abusive behaviours, and they

ran away from home or attempted suicide more often when compared to other children. In line with this, another study in the UK found that 40% of the adolescents with Asperger's Disorder were reported to have been sexually or financially exploited (Balfe & Tantam, 2010). In contrast, Mehtar and Mukaddes (2011) found trauma history in 26.1% of their sample but sexual abuse was uncommon (1.45%).

DISCUSSION

In this study, scientific publications on sexuality and Autism Spectrum Disorders were reviewed. It showed that, in general, sexual development is understudied in this population. Sexual behaviours and desires were observed in, and reported by, a lot of adolescents and adults with ASDs and sexuality proved to be an issue for children, their parents, and other caregivers. This supports the view on sexuality as a normative aspect of adolescent development in people with an ASD. First, some methodological limitations are discussed. The methods, participants, data collection methods, and instruments used in the available studies were very diverse and have varying quality. In most studies parents or caregivers were the source of information and in only a few studies people with an ASD were directly questioned. The number of participants in all studies was small and the groups studied often had wide ranges in age, intelligence, and level of functioning. Several samples consisted of people living in institutions, and this living situation can be of influence on sexual socialization. Only a few studies described high-functioning people with an ASD living in the community. Typically developing control groups were lacking in most studies. The sex ratios in some of the studied groups were not corresponding to that found in ASD. Finally, ASDs were labelled in different ways (e.g. autism vs. autistic disorder) and it was not always clear how, and by whom, people were diagnosed. Instruments to confirm autism features varied from short questionnaires to extensive semi-structured interviews and observations (e.g. AQ vs. ADI-R). These methodological limitations hamper the possibilities to generalize and compare results. Nevertheless, these studies offer insight into a developmental domain in a very specific population that is hard to study.

This review shows that research on sexual development in people with ASDs is scarce. Studies on sexual behaviour were mainly explorative, looking for the occurrence of different sexual behaviours. Masturbation was observed and reported in many of the male samples and also, but less, in female ones. These observational reports showed lower frequencies compared to self-reports in typically developing adolescents and adults. Person-oriented behaviours were observed, although not always with mutual consent, especially in less able groups. Being in a relationship was related to social skills, and led to

more dyadic sexual behaviours. No research was found concerning sexual risk behaviour (e.g. on the use of contraception and condoms), but there has been attention to offending behaviours. The relationship between sexual offending, sexually deviant behaviours, and ASDs remained unclear. A relationship has been suggested based on the prevalence of these behaviours in inpatient ASD groups, and by case reports. No systematic research on the development of these behaviours is available. In two (excluded) studies was screened for ASD symptoms in specific groups in order to explore a relationship between ASD and offensive behaviours: one in detained adolescents suspected of sex offences ('t Hart-Kerkhoffs et al., 2009) and another in files of adult murderers (Lester et al., 2011). Sound diagnostic assessment lacked in both studies, but they also suggested a relationship between ASD and offensive sexual behaviours. In general no systematic research was found on factors that influence sexual development. Little information was available about the sexual partners of the person with an ASD, their skills or knowledge, nor about the interactional processes between partners.

Next to information on sexual behaviours, sexual selfhood is an understudied domain. In general, the majority of people with an ASD demonstrated interest in sexuality. The level of adequate sexual knowledge was unclear, although basic knowledge tended to be average. This did not imply that this knowledge was used in daily living. Again, the level of social functioning was of influence in this transfer. Sexual orientation varied, with indications of high numbers of bi/homosexuals and sometimes feelings of asexuality. No studies compared these youngsters and adults with typically developing people with corresponding sexual orientations and little is known about the well-being of homosexual people with an ASD. In general, sexual well-being and satisfaction was linked with relationship status. The influence of solo-sex on well-being is unknown. There are no studies on the decision-making processes of people with an ASD regarding sexual behaviours (e.g. when feeling ready to engage in sexual intercourse). Gender identity problems frequently arose in case studies, but little is known about these youngsters and gender development in ASDs. de Vries et al. (2010) described a high incidence of ASD in children with gender identity problems (GID) in a gender clinic, and Jones et al. (2011) screened for ASD symptoms in their GID sample, again without formal ASD diagnosis, but systematic research of gender and identity problems in people with ASDs still lack.

Research on sexual socialization has mainly been focused on experiences of parents and caregivers. They appeared crucial in the support of people with an ASD, but, as it seems, they themselves need training and support in dealing with sexuality in children and adolescents with an ASD. Other sources of information such as peers and media, relevant for typically developing adolescents, are understudied, and their importance remains unclear. The research of Mandell et al. (2005) revealed that sexual victimization was frequently a reality

for children an ASD influencing their further sexual development, although these findings were not confirmed in other studies.

Other domains, relevant in autism and in sex research, are underexplored such as information processing in ASDs (sensory, communication, social) and influences on sexuality, decision making processes, the development of expectancies and norms, etc.

CONCLUSION

The existing knowledge on sexual health in adolescents and adults with an ASD is preliminary. Despite this, it is clear that sexuality and relational functioning is an important developmental domain for people with ASDs in contemporary society. Sexuality, as a developmental domain, appears, as in typical development, normative for adolescents with autism. The factors and mechanisms underlying sexual development and sexual health in people with an ASD remain understudied, despite of their relevance for education, prevention, and treatment. Parents, caregivers, and teachers need specific support in dealing with this developmental task. Furthermore, additional training seems relevant for professional caregivers (psychologists, psychiatrists, and allied disciplines) in order to discuss this topic with youngsters and their families, to give them advice and to offer treatment if necessary.

Implications and directions for further research

More research is needed to explore sexual development in adolescents and adults with ASDs, and longitudinal and intervention studies are needed to gain more insight into the relationship between the different domains. A theory or framework driven approach, combining the actual knowledge on sexual health and ASD, could be valuable in developing future research designs and interventions.

Nurses have an important role in general health care, in schools and institutions. In daily practice, nurses and other professionals can actively pay attention to sexuality in their work with people with an ASD. They can offer information, support, inform caregivers and other professionals about aspects of sexuality, and refer to a specialist when needed.

Sexuality, not least among adolescents with ASDs, is a complex domain of individual and social functioning, driven by biological, intra- and interpersonal processes in interaction with many contextual forces, as is true for typically developing people. Awareness of this developmental domain as a part of general well-being is a responsibility of all professionals involved.

CHAPTER 2

Sexuality in adolescent boys with Autism Spectrum Disorder: Self-reported behaviours and attitudes

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ABSTRACT

Differences in sexual functioning of adolescents with and without Autism Spectrum Disorder (ASD) are understudied. In the current study, self-reported sexual behaviours, interests and attitudes of 50 adolescent boys, aged 15 to 18, with at least average intelligence and diagnosed with ASD, were compared with a matched general population control group of 90 boys. Results demonstrated substantial similarity between the groups in terms of sexual behaviours. The only significant difference was that boys with ASD reacted more tolerant towards homosexuality compared to the control group. Results reveal that sexuality is a normative part of adolescent development in high-functioning boys with ASD. Hence, attention should be given to this topic in education and mental health care.

Keywords: Autism – Asperger's Disorder – Sexuality – Sexual behaviour

INTRODUCTION

Over the past few decades, sexuality has become increasingly accepted as a normative part of adolescent development (Tolman and McClelland 2011), yet little is known about sexuality in high-functioning adolescents with Autism Spectrum Disorder (ASD) (Dewinter et al. 2013). The aim of this study was to investigate sexual behaviours and attitudes in a group of adolescent boys diagnosed with ASD and with at least average intelligence. Findings on normative sexual behaviours in the general Western adolescent population serve as a reference point. The possible influence of ASD features on the development of sexual behaviour, as well as the limited research on sexuality and ASD, will be discussed to underpin the hypotheses for this research.

Adolescent sexual behaviours

Until now, research on sexuality in adolescent samples has focussed primarily on sexual behaviours. Other aspects of adult sexuality, however, such as sexual desire, function, arousal and experience, are also part of early adolescent functioning. Studies on these aspects remain scarce (Diamond and Savin-Williams 2009; Fortenberry 2013). Scientific publications on adolescent sexuality in Western countries reveal a decline in age for the onset of puberty. Earlier age for sexual debut was also found, for solo as well as partnered acts. This decline in age of first sexual experiences has stabilised during recent decades. Solo sexual experiences, such as masturbation, are common in early adolescent boys and are shown by about half of the boys at age 12 (Fortenberry 2013; Moore and Rosenthal 2006). A specific sequence in partnered sexual experiences and behaviours has appeared in different studies – starting at around age 13 with kissing, and moving on to embracing, petting above clothes, touching breasts and genitals, masturbating the other, oral stimulation and vaginal intercourse (around 60% at age 18 in the case of the latter) (de Graaf et al. 2012; Diamond and Savin-Williams 2009; Moore and Rosenthal 2006). Only a minority of adolescents reported anal intercourse. Around 90% of adolescents defined themselves as heterosexual, although uncertainty about sexual orientation is common in adolescents (Diamond and Savin-Williams 2009; Moore and Rosenthal 2006).

ASD and sexuality

There is a dearth of knowledge on the prevalence of solo and partnered sexual behaviours, as well as on the age of sexual debut, in adolescents with ASD. Although there is no evidence that physical maturation of adolescents with ASD differs from that of typically developing peers (Gabriels and Van Bourgondien 2007), it can be assumed that ASD features in adolescents influence sexual development and functioning in different ways. Mechanisms that might play a part are described below.

First, *behavioural and information processing characteristics* in ASD, such as specific sensory interests (e.g., interest in specific aspects such as hair), hyper- or hyposensitivity (e.g., hypersensitivity towards touching), preoccupations, and compulsiveness (e.g., specific rituals), may directly influence sexual experience and behaviours of people with ASD. Second, qualitative impairments in ASD in the *social and communicative domain* are also likely to have an impact on the sexual development of adolescents with ASD. These features frequently hamper the development of friendships and romantic relationships, diminish opportunities to learn about sexuality from peers and influence one's judgement to apply sexuality in a socially acceptable way or in interpreting (sexual) intentions of others. Communicative impairments might result in literal or incorrect interpretations of information relating to sexuality. On both explicit and implicit levels, information about sexuality and sexual codes might not be clear to people with ASD (Gabriels and Van Bourgondien 2007). In addition to the role of specific ASD features, *characteristics of the social contexts* of the boys with ASD could also influence their sexual development (Smith et al. 2005). Sexual socialisation of adolescents by parents, teachers, and other caregivers might differ depending on their opinions regarding sexuality and ASD, their skills in discussing these topics, or their concerns about the skills of their children with ASD. Societal views on sexuality and autism also influence education and parenting. Bertilsdotter Rosqvist (2013) discerned different views on sexuality in autism over the past few decades, varying from the denial of sexuality in people with ASD (asexuality discourse) to a focus on abnormality (deficit discourse), or a normative discourse based on sexual development of neurotypical people (neuronormative discourse) versus an autistic sexuality.

Research on sexuality and ASD

Recently, the existing research on sexuality and ASD was reviewed according to the three domains discerned by Tolman and McClelland (2011): behavioural aspects of sexuality, sexual selfhood, and sexual socialisation (Dewinter et al. 2013). Given the aim of the current study, only findings on behavioural aspects are discussed below. This knowledge of sexual behaviour in people with an ASD should be interpreted in light of different methodological limitations. First, the characteristics of the groups studied differ, both between and within studies, regarding participants' intellectual capacities, autism features, sex, age, and level of functioning. Most of the available results on sexuality and ASD are based on the study of adults or mixed-age groups. Second, most studies included small numbers of participants. Both these aspects hamper comparability and generalizability of the available findings. Third, even though adolescents display most sexual behaviours in private, researchers mostly approached caregivers or parents as informants (Haracopos and Pedersen 1992; Hellemans et al. 2007; Stokes et al. 2007; Stokes and Kaur 2005). The validity of data based on

observations by others is questionable and different authors have stressed the importance of questioning the people with ASD themselves (Haracopos and Pedersen 1992; Hellemans et al. 2007). Studies using self-report only included adult participants (Byers et al. 2013; Gilmour et al. 2012; Hénault and Attwood 2006; Ousley and Mesibov 1991).

The results to date reveal that the majority of people with at least average intelligence and ASD are sexually active – mostly in a solitary manner, in the form of sexual interest and masturbation (Byers et al. 2013; Haracopos and Pedersen 1992; Hellemans et al. 2007; Ousley and Mesibov 1991), with fewer people having partner-oriented sex (Byers et al. 2012; Hellemans et al. 2007; Hénault and Attwood 2006). Findings on sexual orientation suggest a higher prevalence of homo- or bisexual feelings in people with ASD compared to the general population (Byers et al. 2013; Gilmour et al. 2012; Hellemans et al. 2007). Only a small group of adults with ASD reported feelings of asexuality (Gilmour et al. 2012). A number of studies and case reports describe sexual problems (e.g., offensive behaviours) and specific sexual behaviours (e.g., paraphilias) in people with ASD (Baron-Cohen 1988; Bleil Walters et al. 2013; Chan and Saluja 2011; Cooper et al. 1993; Griffin-Shelley 2010; Hellemans et al. 2007; Kohn et al. 1998; Milton et al. 2002; Murrie et al. 2002; Ray et al. 2004; Silva et al. 2002). It remains undetermined, however, whether there is a higher prevalence of problematic behaviour and negative sexual experiences in people with ASD compared to the general population. Mandell et al. (2005) found sexual victimisation in one out of six children with ASD treated in community mental health services, although another study (Mehtar and Mukaddes 2011) revealed lower rates of trauma history. The victimised children in the first study had a higher risk of becoming sexually aggressive and abusive themselves. Furthermore, different studies describe other problematic aspects of sexual development and functioning in people with ASD, such as gender identity problems (de Vries et al. 2010), excessive masturbating, inadequate masturbation techniques, and masturbation in public places (Haracopos and Pedersen 1992; Hellemans et al. 2007).

THE CURRENT STUDY

The main goal of this study was to gain insight into the prevalence of sexual behaviours and experiences of adolescent boys clinically diagnosed with ASD, by focussing on a homogeneous group in terms of intellectual ability, cultural background, age, and diagnosis. The expectation was that these findings would offer insight into the normativity of different sexual behaviours and experiences in high-functioning adolescent boys with ASD. A second goal was to compare self-reported sexual behaviours, attitudes, and interests of adolescent boys with ASD with those of matched peers in the general population. Four basic hypotheses (H1-4) were put forward. First, boys with ASD and the control group have comparable lifetime experience with solitary

sexual behaviours such as masturbation, experience with orgasm, and sexual interest (e.g., viewing explicit sexual materials) (H1). Although it is accepted that physical sexual maturation does not differentiate the ASD and control groups, earlier studies found lower percentages of people with ASD reporting solo sex. We expected, however, that reliance on parent- and caregiver-report explains the lower frequencies regarding solo sexual experiences in the ASD group, resulting in an underestimation of solo sexual experience in earlier studies. Second, given the social limitations inherent in ASD, the expectation was that boys in the ASD group have less experience with partner-oriented sexual behaviours (H2). This could be explained by the social and communicative impairments of the boys with ASD. Third, higher frequencies of victimisation and offending behaviours in the ASD group were also assumed, based on earlier research (Mandell et al. 2005) (H3). Finally, following earlier findings (Hellemans et al. 2007), we expected higher levels of homosexual experiences and homo- or bisexual feelings in the ASD group (H4). Alongside these four hypotheses, we explored attitudes and online behaviours relating to sexuality. Both these aspects remain understudied in adolescents with ASD. Sexual opinions and attitudes are related to sexual behaviour (Fortenberry 2013), making exploration relevant. Sexually explicit media can also influence sexual behaviour in adolescents (Braun-Courville and Rojas 2009). However, in adolescents with ASD, rates of social media use seemed low (Mazurek et al. 2012) and not as important for romantic learning compared with controls (Stokes et al. 2007). Self-report on the use of sexually explicit media and use of internet for sexuality related means by adolescents with ASD is not available.

METHODS

Participants

Participants in this study were native Dutch and Belgian boys aged 15 to 18, with at least average intelligence and diagnosed by mental health professionals with an Autistic Disorder or Asperger's Disorder (APA 2000). All participants were high-functioning; they had to attend regular classes or score above 70 for full scale IQ (following Hellemans et al. 2007) on a standard intelligence measure. Since sexual development gains momentum during adolescence, the age range of the participants was limited to increase homogeneity. Given the differences in sexual development and behaviours between boys and girls, only boys were recruited (Byers et al. 2013; Tolman et al. 2010). The prevalence of ASD is also higher in boys compared with girls: 2:1 for Autistic Disorder; 4:1 for Asperger's Disorder (Levy et al. 2009). Comorbid disorders were no cause for exclusion except in the case of acute psychotic symptoms. Adolescents living in institutions for adolescents with ASD and average intelligence, as well as others living at home and receiving different types of care, were approached.

Controls

The control data were selected from a large survey study on sexual health in young people aged between 12 and 25 in the Netherlands. The authors (de Graaf et al. 2012) of this survey kindly provided us with the original 'Sex under the age of 25 II' data. The participants in the original study were recruited in schools and through Municipal Administrative Systems. They completed the surveys at home or in classrooms. No information was available regarding psychiatric diagnosis in the control group. Although it is unknown if any of the boys in the control group were diagnosed with a psychiatric or developmental disorder, less than the population prevalence (e.g., .6–1.16% for ASD (Levy et al. 2009)) is to be expected. Matching took place based on age, ethnicity, educational level, and sex.

Materials

Sexual functioning

All boys completed a computerized survey on sexual health that was developed for the 'Sex under the age of age 25 II' study by de Graaf et al. (2012), from which the controls were drawn. Questions in this survey were easily understandable formulated and specific concepts were explained next to each question. Most questions were closed multiple-choice answer formats. These characteristics made the questions suited to adolescents with ASD. The survey consisted of a maximum of 172 questions and was automatically adjusted to the characteristics and responses of the participants, so that respondents did not receive inapplicable questions. The survey covered a range of themes relating to sexuality: love and relationships, sexual experiences, partners, evaluation of sexual contacts, attitudes and knowledge, sexual orientation, use of condoms and other contraceptives, offensive behaviour and victimisation, sexual problems, internet behaviours, alcohol and drug use, communication, and sex education. The report on the results of the 'Sex under the age of 25 II' survey describes the construction of the questionnaire. Most items were selected from existing scales and questionnaires. There is no external criterion to test validity. Face validity, however, is good.

Five scales measuring attitudes and feelings were computed. Item scores for each scale were added up and divided by the number of items in the scale. The scale 'Permissiveness towards sexual intercourse' (α=.69) consisted of four four-point Likert-type items (e.g., 'How do you feel about intercourse before marriage?') scored from 1 ('not good at all') to 4 ('totally good'). Higher scores reflect a more liberal attitude towards sexual contacts. 'Gender roles' (α=.69) included four items (e.g., 'How do you feel about a girl chatting up a boy?') with five response levels from 1 ('not good at all') to 5 ('totally good'). Higher scores on this scale reflect less gender-related permissiveness (e.g., a boy can have sex with a lot of girls, but a girl cannot have sex with a lot of boys). The scale 'Acceptance of homosexuality' (α=.67)

consisted of three questions (e.g., 'How do you feel about two boys making love?' and 'If your best friend tells you he is gay, would you stop the friendship?'), with five answering categories from 1 ('not good at all') to 5 ('totally good') for the first example and 1 ('sure I would') to 5 ('sure I wouldn't') for the second. Higher scores on this scale reflect more tolerance of homosexuality. 'Positive feelings about sexuality' (α=.76) had three items (e.g., 'Sex is important to me') and 'Negative feelings about sexuality' (α=.84) contained five items (e.g., 'I feel guilty after masturbating') with five possible responses for each from 1 ('totally agree') to 5 ('totally disagree'). Higher scores reflect less positive and less negative scores about sexuality respectively.

ASD

All boys were clinically diagnosed with either Autistic Disorder or Asperger's Disorder before they entered the study. ASD features were assessed by administration of the Autism Diagnostic Observation Schedule (ADOS) module 4 (fluent speech) (Lord et al. 1999) to the participating boys and the Autism Diagnostic Interview-Revised (Rutter et al. 2003) to their parents. The first author (JD), who is qualified for research purposes in both ADI-R and ADOS, conducted all administrations.

Procedure

This study was approved after ethical review (Medical Ethical Committee reference NL34563.097.11 in the Netherlands and approval 4112 by the Institutional Review Board ZNA/OCMW in Antwerp, Belgium). Professionals, working with boys with ASD in different institutions and schools, invited eligible participants. None of the participants was dependent on the researchers for treatment. Parents and adolescents received an information letter and leaflets. Potential participants could contact the researcher to obtain further information or to refuse participation. Parents were contacted again after 10 days if no response was received. We also posted a call for participation on the website of the Dutch Autism Association.

Administration of the survey and ASD assessments took place at home, at school or in the hospital or institution where the adolescent resided. Participants received additional information on the study at the start of every appointment. All boys and their parents gave written informed consent. In most cases, the ADOS was conducted before the completion of the survey on sexuality, because this provided the opportunity for the boys to become acquainted with the researcher. The boys completed the online survey (SO25II) in private with the researcher nearby, so that they could ask for help or additional information. They were told that a variety of behaviours and opinions relating to sexuality would be asked about, in which they may or may have not been involved. They received a neutral username and password to log in anonymously. Some boys asked for help or preferred to have the

questions read aloud by the researcher. The adolescents regularly reported personal experiences or asked for clarification of questions. Two boys preferred to complete the survey on their own at home. It took 90 minutes for the boys to complete the ADOS and survey. The administration of the ADI-R took on average two hours. Participants received a €5 voucher after completing the survey.

Power analysis and statistical analyses

According to a priori power analysis (α=.05, 1-β=.80), a group size of 50 participants was necessary in order to detect medium- to large-sized effects between the two groups (ASD and control) when looking at differences between means and frequencies (Cohen 1988). Data were analysed using SPSS21. Mann-Whitney U tests (exact two-sided) were used to compare medians and group distributions. Chi-square (χ^2) tests were run to compare frequencies and exact two-side probabilities were reported. The Fisher's exact test, the exact probability of chi-square, was used when the expected frequencies in cells were too low, due to the relatively small sample size. The large number of comparisons inflates the risk of type I errors. A Bonferroni correction would result in higher risk for type II errors. Therefore, a type I error rate of α=.01 was adopted. Cramer's *V* is the effect size for significant results of chi-square (χ^2) tests. Given the power calculation, only medium (Cramer's *V*=.3 to .5) to large (Cramer's *V*>.5) effects are interpreted. Effect size *r* is reported for Mann-Whitney *U* tests. Cohen (1988) suggested that *r*=.1 represents a small effect, *r*=.3 a medium effect, and *r*=.5 a large effect. Since questions were omitted depending on earlier answers of participants, not all boys had to answer all questions, so it will be explicitly noted if total *N* was lower than 50.

RESULTS

Sample characteristics

One hundred and forty-six boys and their parents received information about this project. Fifty-one boys agreed to participate and completed the computerized survey on sexual health. Reasons for non-participation varied. In most cases, parents stated that the psychological condition of their son did not allow for participation, or mentioned that their son had a lack of interest in sexuality or refused to talk about sexuality. No other information on the non-responders was available. One participant reported that he did not dare to answer honestly questions pertaining to homosexuality, resulting in the exclusion of his data from the analysis. The remaining 50 boys (Table 1) were matched to the maximal possible stratified random sample selected from the study 'Sex under the age of 25 II' (*N*=3926 boys and 3915 girls) (de Graaf et al. 2012).

Table 1. Characteristics of participants with ASD

		ASD % (*n*) (*N*=50)		
ASD	Autistic Disorder	40 (20)		
	Asperger's Disorder	60 (30)		
Comorbid disorders	Attention Deficit Hyperactivity Disorder	24 (12)		
	Learning Disorders	8 (4)		
	Anxiety Disorders	4 (2)		
	Posttraumatic Stress Disorder	2 (1)		
	Tourette's Disorder	2 (1)		
Living situation	Home	70 (35)		
	Group home	16 (8)		
	Residential psychiatric treatment	12 (6)		
	Day care treatment	2 (1)		
Educational level	High	42 (21)		
	Low	58 (29)		
		M	***SD***	**Range**
Age	ASD	16.65	.78	15.04–18.02
Intelligence (IQ)	Full scale (*n*=42)	104.29	15.62	76–142
	Verbal scale (*n*=40)	107.83	15.15	80–142
	Performal scale (*n*=40)	100.68	16.26	70–140

The control group consisted of 90 boys living in the Netherlands. Matching took place based on age (15 to 18), sex (male), ethnicity (Dutch) and educational level (low, i.e., prevocational, vs. high). Both groups did not differ regarding age ($t(138)=.27$, $p=.79$) or educational level ($\chi^2(1)=.40$, $p=.84$).

Autism features

Mental health professionals in multi-disciplinary teams diagnosed all participants in the ASD group (Autistic Disorder or Asperger's Disorder) before inclusion. Of the 50 boys with ASD, 45 agreed to the administration of ADOS after inclusion. Thirty-four of these 45 boys (sensitivity *SE*=.76) met the cut-off scores for ASD on the ADOS module 4 algorithm (16 Autistic Disorder, 18 Asperger's Disorder), and 31 (*SE*=.69) when using the new Gotham criteria, developed for ADOS module 3 (Gotham et al. 2007). Bastiaansen et al. (2011) found a comparable sensitivity of the ADOS in their sample of high-functioning adults: in their sample, a cut-off score of five resulted in a higher sensitivity, in balance with specificity. In our group, using the revised algorithm and cut-off score of five, sensitivity increased to .90.

Thirty-six parents agreed for the ADI-R to be administered, of which 14 met the algorithm cut-off scores (sensitivity *SE*=.39). Applying the convention of allowing a diagnosis of ASD if the ADI-R scores meet the cut-off on two of three domains and miss the cut-off on the third by one point (Rutter et al. 2003) resulted in 24 positives (*SE*=.67). Comparison of the groups that did and did not meet the cut-off scores of both ADI-R and ADOS revealed no major differences in relation to sexual behaviours.

Sexual behaviour

Comparable percentages of boys in the ASD and control group reported having experienced different romantic and sexual behaviours – solo as well as partnered (Table 2).

The majority of boys with ASD had been in love (82%) and dated a partner (70%). Almost all boys reported masturbation (ASD 94%) and had experienced an orgasm (ASD 90%). About half of the boys at this age confirmed French kissing and petting their partner above clothes. A

Table 2. Sexual behaviours and age of first experience

	Experienced this				Age first time[4]			
	ASD % (*n*) (*N*=50)	Control % (*n*) (*N*=90)	X^2	*p*	ASD *M*	Control *M*	*t*	*p*
Has been in love	82 (41)	85.6 (77)	.31	.63	n/a[1]	n/a[1]	n/a[1]	n/a[1]
Masturbation	94 (47)	90.0 (81)	n/a[1]	.54	12.93	13.47	1.44	.15
Orgasm	90 (45)	85.6 (77)	.57	.60	13.34	13.63	.85	.40
Dating	70 (35)	73.3 (66)	.18	.70	12.99	12.65	-.61	.54
French kissing	56 (28)	65.6 (59)	1.25	.28	14.50	13.99	-1.13	.26
Petting with clothes on	52 (26)	63.0 (57)	1.70	.21	14.96	14.66	-.82	.41
Masturbating another	40 (20)	41.0 (37)	.02	1.00	15.55	15.50	-.17	.86
Being masturbated	34 (17)	37.0 (33)	.10	.85	15.32	15.38	.15	.88
Oral sex[2] (active)	22 (11)	25.5 (23)	.06	.82	15.50	15.72	.45	.66
Oral sex[2] (passive)	22 (11)	32.2 (29)	.37	.65	15.42	15.81	.91	.37
Vaginal intercourse	24 (12)	33.3 (30)	1.33	.34	15.42	16.03	1.61	.12
Anal sex[2]	6 (3)	3.3 (3)	n/a[1]	.37	14.17	15.17	1.06	.35
Only feels attracted to girls	88 (44)	93.3 (84)	n/a[1]	.35	n/a[1]	n/a[1]	n/a[1]	n/a[1]
Tried or would like to try making love with a boy	18 (9)	12.2 (11)	.87	.45	n/a[1]	n/a[1]	n/a[1]	n/a[1]

[1]not applicable, Fisher's exact was used, [2]question asked to boys with other partnered experience ASD *n*=29, controls *n*=65, [3]of those who have experience

substantial number of boys had experience with manual and oral stimulation. About a quarter of the boys with ASD reported vaginal intercourse. Few boys had experienced anal sex. Both groups reported comparable ages of sexual debut (first time engaging in these different sexual behaviours). These results support the first hypothesis and refute the second (H1-2).

Of the boys with ASD with partnered sexual experience (*n*=26), 11–50% reported sexual problems (e.g., diminished sexual arousal, delayed or premature orgasm and pain), comparable with rates in the control group. However, this group was too small to interpret these findings. Only a small number of boys reported that they had been forced into sexual behaviours (*n*=2 in the ASD group) or had used sexual coercion (ASD *n*=3) (H3).

Most boys, in both the ASD and the control group, reported feeling attracted only to girls. Some reported having made love to another boy or being willing to try this out. No significant differences ($p>.01$) between the ASD group and control group were found. These findings result in the rejection of the fourth hypothesis (H4).

Attitudes towards sexuality

Participants with ASD and controls reacted equally permissively to statements about sexual contacts in different male–female relationships (Table 3 for scale means, item frequencies are added in text for illustration).

Double standards in the role of boys and girls in flirting and sexual behaviour (gender role) were not found. The majority of boys in both groups disapproved of sexual contacts with many different partners in both boys and girls (ASD 68% in the case of girls and 62% for boys). The boys with ASD were significantly less disapproving towards homosexuality (acceptance of homosexuality). More boys with ASD (76%) approved sexual contact between two boys, compared with controls (37.8%) ($\chi^2(1)=18.8$, $p<.01$, Cramer's $V=.37$). The majority of boys in both the ASD and control group felt positive about sexual contacts between two girls (ASD 92%, control 78.9%). The boys with ASD and controls disagreed with negative statements relating to sexuality and had a neutral or positive response to positive sexuality-related statements.

Table 3. Feelings towards sexuality, gender roles and homosexuality

	ASD	Controls				
	Mdn	***Mdn***	***U***	***z***	***p***	***r***
Permissiveness towards sexuality[1] (1–4)	3.25	3.25	2134.0	-.51	.61	-.04
Gender roles[1] (1–5)	3.12	3.00	2118.5	-.58	.57	.05
Acceptance of homosexuality[2] (1–5)	4.00	3.33	1012.0	-4.50	<.01	.39
Positive feelings about sexuality[1] (1–5)	2.67	2.67	1971.0	-1.22	.22	.10
Negative feelings about sexuality[1] (1–5)	4.60	4.40	2228.5	-.09	.93	-.01

[1]ASD *n*=50, Controls *n*=90, [2]ASD *n*=45, Controls *n*=86

Internet and sexually explicit materials

About half of the boys with ASD talked about sex on the internet in the previous six months (Table 4).

Table 4. Use of explicit sexual materials and online sexuality during last six months

Media	ASD % (*n*) (*N*=50)	Controls % (*n*) (*N*=90)	X^2	*p*
Porn magazine	36 (18)	36.7 (33)	.01	1.00
Video clip with nudity	70 (35)	75.6 (68)	.51	.55
Sex movie on TV	22 (11)	30.0 (27)	1.04	.33
Sex movie on DVD	8 (4)	14.4 (13)	1.25	.30
Porn on the internet	76 (38)	73.3 (66)	.12	.84
Sex line	4 (2)	3.3 (3)	n/a[1]	1.00
Any	86 (43)	87.8 (79)	2.54	.88
On the internet				
Talked about sex	46 (23)	27.7 (25)	4.74	.04
Flirted	38 (19)	36.7 (33)	.02	1.00
Showed genitals or bottom	8 (4)	2.2 (2)	n/a[1]	.19
Send naked pictures or sex movies of self	6 (3)	0.0 (0)	n/a[1]	.04
Send naked pictures or sex movies of others	8 (4)	4.4 (4)	n/a[1]	.46
Cybersex	12 (6)	2.2 (2)	n/a[1]	.02
Any	54 (27)	43.3 (39)	7.44	.19

[1]not applicable, Fisher's exact was used

The boys with ASD viewed explicit sexual images in porn magazines (36%), in video clips containing nudity (70%), in sex movies (22%), and on porn websites (76%). Most boys viewed any of the sexually explicit media (86%) and about half (54%) of the boys with ASD used the internet for at least one sexuality-related activity. Participants with ASD and controls did not significantly differ (p>.01) regarding their experience with sexual explicit media and sexuality on the internet.

DISCUSSION

The aim of this study was to enhance insight into sexual and relational experiences in a group of high-functioning adolescent boys with ASD. The results of this study confirm the expectations of a high prevalence of solo sexual behaviours (H1) but refute earlier assumptions regarding fewer partnered sexual experiences (Hellemans et al. 2007), later

sexual debut (Stokes and Kaur 2005) (H2) and higher frequency of same-sex feelings or experiences (H4) in boys with ASD when compared with boys in the general population. Sexual victimization and offending (H3) were hardly found. Both groups had permissive attitudes towards sexuality, no explicit gender role expectations, and higher positive and lower negative attitudes towards sexuality. The participants with ASD were significantly more accepting towards homosexuality, compared to controls. Finally, the internet has become an arena for sexuality-related exchanges for all adolescents, including those with ASD.

The results of this study support the earlier findings by Hellemans et al. (2007) on age-appropriate sexual experience in high-functioning boys with ASD and reveal no differences in lifetime sexual experience of boys with ASD and their peers in the general population. The higher frequencies regarding sexual experience in this study compared with findings of earlier studies (Haracopos and Pedersen 1992; Hellemans et al. 2007) are due, at least partly, to the use of self- versus parent- or caregiver-report. These observers frequently stated that they had insufficient knowledge of specific behaviours or feelings of the children under study (Hellemans et al. 2007). Clearly, self-report by boys with ASD may be considered more accurate than reports by parents or caregivers.

Adolescent sexuality and ASD

Based on the results of this study, a typical high-functioning adolescent boy with ASD starts masturbating at around age 13 falls in love in the same period and experiences his first orgasm shortly afterwards. Before the age of 16, he has a relationship with a girl and starts kissing and petting. One in 10 boys doubts his preference for girls or has fantasies about sex with another boy The typical boy with ASD thinks positively about sex, is rather permissive and is not bothered about same-sex interests of peers. A substantial part (20–34%) has experienced other partnered sexual behaviours (manual and oral sex) and one in five has sexual intercourse in this period. The boys will probably have viewed sexually explicit materials and half of them used the internet for sexual means. The prevalence of sex-related problems in adolescents needs further attention in research.

Although the results of this study demonstrated comparable trajectories in the sexual development of boys with ASD and their peers in the general population, differences cannot be ruled out. The results of this study do not offer information on the frequency, context or quality of the different sexual experiences since only the presence or absence of experiences was questioned. Remarks and questions by the boys with ASD during data collection indicated that some of them had indeed experienced concerns or behaved in inappropriate ways. Taken together, ASD features seem not to influence *whether* high functioning adolescent boys with ASD have solo and partnered sexual experience; however, little is known about *how*, in which circumstances and with whom.

The results of this study highlight the importance of sex education for high-functioning adolescent boys with ASD in order to support their sexual development as a positive part of human functioning. This study also has implications for the age at which to offer sex education. In contrast with earlier findings (Stokes and Kaur 2005), no delay in sexual debut was found. Sex education attuned to the developmental stage of boys with ASD should support these boys to understand their bodily changes and sexual reactions, feelings and behaviours. Given the social, communicative and behavioural features inherent in ASD, sex education should be tailored to the specific impairments and needs of these boys in order to strengthen their insight and skills when starting romantic relationships and enable them to enjoy sexuality in a safe and respectful way. Attention should be given to solo as well as partnered sexuality, in real life and online. It is possible, in contradiction with earlier findings (Mazurek et al. 2012), that online contacts are easier to make or more appealing than face-to-face contacts for some boys in the ASD group and can be a 'window on the world', offering a way to initiate romantic and sexual contacts. Different risks relating to online sexuality-related activities for boys with ASD could be imagined, however only a small number of boys with ASD reported online behaviours that may cause concern.

Same-sex feelings and ASD

This study did not confirm earlier findings regarding a higher prevalence of homosexual feelings and behaviours in boys with ASD (Gilmour et al. 2012; Hellemans et al. 2007). However, the ASD group was far more tolerant than the control group towards homosexuality in society. It is not clear how this difference in tolerance can be explained. Different mechanisms may be at work: lower sensitivity to social norms and stereotyped gender roles in the boys with ASD, a higher tolerance for being different, a socially desirable response style, lower recognition of their own sexual preferences, or having more homosexual feelings themselves. Conversely, a greater tolerance of homosexuality could make same-sex experimentation more acceptable, but this is not reflected in same-sex experiences in this study. Attention to this topic in education is, however, advisable.

Victimisation, offending and ASD

Earlier findings relating to a high prevalence of sexual victimisation in people with ASD (Mandell et al. 2005) were not confirmed in this sample. Recruitment strategies might be of influence: Mandell et al. (2005) studied children in mental health services who might have suffered more victimisation, while not all of this study's participants received mental health care. Furthermore, it is possible that victims might have refused to participate in our study. Sexual offending was also hardly found in this study. Only a very small number of boys in the ASD group reported having forced another into sexual activities, which puts earlier findings on the relation between ASD features in boys accused of sex offences ('t Hart-Kerkhoffs et

al. 2009) into perspective. Earlier studies showed a comparable and even higher percentage of boys in the general population who confirmed that they had forced someone into sexual behaviours, ranging from 3.6% of boys in the Netherlands (de Graaf et al. 2012) to 12% in a Norwegian group of boys (Seto et al. 2010).

Limitations, strengths, and further research

The results should be interpreted in light of the strengths and limitations of this study. Characteristics of the ASD group might limit generalizability. The low ADOS scores might indicate that some of the participants had only mild ASD features. A substantial proportion of the boys with ASD had comorbid disorders, especially ADHD, which possibly influenced their sexual functioning. For example, Flory et al. (2006) found an increased likelihood for adolescents with (comorbid) ADHD to engage in risky sexual behaviours. Given that a quarter of the boys with ASD, in this study, had comorbid ADHD, this finding might have resulted in an overestimation of sexual experience compared to boys with ASD without ADHD. Recruitment bias could also have influenced the results of this study; people volunteering in sex research are more open to sexuality, have more sexual experience (Bogaert 1996), less guilt (Strassberg and Lowe 1995), less conservative sexual opinions, more novelty-seeking behaviour, earlier onset of sexual behaviour, and more adverse sexual experiences (Dunne et al. 1997). However, Dunne et al. (1997) stated that the differences between participants' and non-participants' reports were small and the more experienced participants tend to underreport. Different parents refused to let their sons participate in this study, stating that the boys were not interested in sexuality. This might have resulted in the selection of boys with ASD who were more interested in sexuality than others, resulting in an overestimation of lifetime sexual experience. On the other hand, in the general population, parents tend to underestimate the sexual experience of their children (Jaccard et al. 1998; Mollborn and Everett 2010). Other reasons for non-participation, such as negative feelings relating to sexuality or the psychological condition of the boys, might also have biased this study's results. For example, boys that were abused or had offended, and boys that experienced uncertainty relating to sexuality could have declined participation.

Notwithstanding the efforts made to minimize report bias (Tourangeau and Yan 2007), its influence on a sensitive issue such as sexuality cannot be ruled out. In addition, this survey did not contain questions on some specific sexual behaviours (e.g., paraphilias and compulsive masturbation), although they were found in earlier studies of people with ASD. Finally, the absence of significant differences in sexual experience between the boys with ASD and the controls could be due to the selection and the experience of the control group. The proportion of boys in the control group who had sexual intercourse is lower than the findings of de Graaf et al. (2012) (38% of boys aged 15 to 18), but comparable with findings

of the National Survey of Sexual Health and Behavior (http://www.nationalsexstudy.indiana.edu). If the boys in the control group were less sexually experienced than their peers, it might be possible that partnered sexual behaviours are less common in boys with ASD than in boys in the general population.

Notwithstanding these limitations, this study is, to the best of our knowledge, the first to describe self-reported relational and sexual functioning, and opinions about sexuality in high-functioning adolescent boys with ASD. This offers a unique insight into their experience, beliefs and behaviour relating to sexuality.

Replication of these findings in other ASD samples of all cognitive and functional levels is needed. In addition, several questions for further research remain. Follow-up and qualitative studies are necessary to gain more in-depth insight into boys' sexual development and well-being. The role of the context (e.g., growing up in a relatively conservative family where sexuality may be less easily discussed) or the availability of sex education is another domain for further study. In addition, longitudinal studies are needed to explore sexual development. Developmental differences between boys who have more versus less sexual experience or who avoid sexuality might offer clues for intervention and support. Finally, sexual development in female adolescents with ASD remains understudied.

CONCLUSION

This study demonstrated that having ASD has little influence on the lifetime experience of sexual behaviours, feelings and attitudes in high-functioning adolescent boys. The findings of this study refute the old asexuality beliefs as well as put the deficit discourse on ASD and sexuality into perspective (Bertilsdotter Rosqvist 2013; Koller 2000; Torisky and Torisky 1985). In addition, our results counter the earlier findings that adolescents with ASD are delayed in their sexual development (Stokes and Kaur 2005). The results of this study broaden recent findings on positive sexual functioning in adults to adolescents with ASD (Byers et al. 2013). However, some boys might experience or demonstrate sexual problems, as was indicated by the remarks and questions of some of the boys with ASD in this study and based on the existing case reports. Taken together, we are convinced that an integrated approach (Tolman and McClelland 2011) seems justified – i.e., accepting sexuality as a normative part of adolescent development while also giving attention to the possible impact of ASD features on learning and daily functioning relating to sexuality. Education and communication regarding sexuality is thus as important for boys with ASD as it is for their peers. Early attention to sexuality can prepare adolescents with ASD to understand their sexual development and enhance a positive sexual development. Open and concrete

communication about sexuality with adolescent boys with ASD offers them the opportunity to raise questions and to discuss worries or difficulties. Parents, caregivers and mental health professionals should be prepared and trained to support children and adolescents with ASD in their sexual development as a normative and positive part of these adolescents' functioning.

CHAPTER 3

Brief communication: Parental awareness of sexual experience in adolescent boys with Autism Spectrum Disorder

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ABSTRACT

Parent report and adolescent self-report data on lifetime sexual experience in adolescents with ASD were compared in 43 parent-adolescent dyads. Parents tended to underestimate the lifetime sexual experience of their sons, particularly solo sexual experiences such as masturbation and experience with orgasm. Parental underestimation and unawareness of adolescents' sexual experience may influence communication and education about sex and sexuality in families. These findings have implications for the interpretation of earlier research, based on parent and caregiver reports, on sexuality in adolescents with ASD.

Keywords: Autism Spectrum Disorder – Adolescence – Sexuality – Parental awareness

INTRODUCTION

A number of recent studies have asked adolescents and adults with Autism Spectrum Disorders (ASDs) about their sexual experience and sexuality (Byers et al., 2012, 2013; Dewinter, Vermeiren, Vanwesenbeeck, Lobbestael, & Van Nieuwenhuizen, 2015). These studies, which were based on self-report, showed that the lifetime sexual experience of high-functioning adolescent boys with ASD was comparable to that of their peers in the general population (Dewinter et al., 2015) or demonstrated healthy sexual functioning in adults with ASD (Byers et al., 2012, 2013). Sexual health (WHO, 2006) refers to a state of well-being and a positive, respectful, safe, and pleasurable approach of sexuality and sexual relationships. Earlier research based on parent (Holmes & Himle, 2014) or caregiver reports (Hellemans et al., 2007), however, showed that parents and caregivers thought that adolescents with ASD had less experience of different sexual behaviours than was suggested by adolescents' self-reports in a recent study (Dewinter et al., 2015). The difference between these two types of data may reflect parental underestimation of adolescents' sexual experience. Research (e.g. Jaccard, Dittus, & Gordon, 1998; Liddon, Michael, Dittus, & Markowitz, 2013; Mollborn & Everett, 2010) demonstrated that parents of boys in the general population also underestimate the sexual experience (mainly sexual intercourse) of their adolescent children. So, parents of boys with ASD might not differ in their knowledge on the sexual experience of their sons compared to parents of non-ASD peers.

Since parents are the primary sex educators of their children (SIECUS, 2004), parents' underestimation and unawareness of their sons' sexual experience may have implications for communication and education related to these topics. Earlier research (Ballan, 2012; Ruble & Dalrymple, 1993) indicated that parents of children with ASD were less inclined to discuss issues of sexuality with their children if they believed that their child's condition precluded a romantic relationship. Parents also reported uncertainty about what, when and how to tell their children about sex and sexuality (Nichols & Blakeley-Smith, 2009). This uncertainty may be due to a combination of lack of knowledge about sexual development in adolescents with ASD, and lack of awareness or underestimation of their adolescent child's sexual experience. Parental underestimation of, and unawareness about the sexual experience of adolescents with ASD may directly influence parent-adolescent communication about sex and sexuality, and the timing of parental sex education. Offering timely information about sexuality and how to deal with it can promote healthy sexual development in adolescents with ASD and help to prevent inappropriate or aversive sexual behaviours and experiences. Limited sexuality education might lead to unawareness in adolescents of conventions related to sexuality and relationships, to frustration (e.g. ineffective masturbation practices), and self-harm (e.g. excessive masturbation).

Sexuality development encompasses more than experience with solo and partnered sexual acts: it is about mind and body, individual experiences and attributes (e.g. desire, pleasure, identity, preference, fantasies, roles, and norms), relationships, and social influences (e.g. law, mores, and culture) (Tolman & Diamond, 2014a; WHO, 2006). This study compared parent and adolescent reports of lifetime solo and partnered sexual behaviour in a sample of adolescent boys with ASD. We assumed that the boys would report more sexual experience than their parents reported being aware of.

METHOD

Participants

The inclusion criteria for adolescent participants were male sex; age 15-18 years; Dutch or Belgian cultural background and a diagnosis of an Autistic Disorder or Asperger's Disorder. Adolescent participants also had to be attending mainstream school or score in the below average range or above on standardised intelligence measures (Full-Scale IQ > 70). Comorbid psychopathology, other than florid psychotic symptoms, was not an exclusion criterion. The parents of all adolescent participants could participate in the study. ASD features were assessed with the ADOS (Autism Diagnostic Observation Schedule), module 4 (fluent speech) (Lord et al., 1999). One hundred and forty-six boys and their parents received information on this study. The parents of 44 of the participating boys (N = 51) agreed to participate in this study and completed a questionnaire. One parent-adolescent dyad was excluded because the boy reported that he did not dare to answer the questions honestly, leaving a sample of 43 dyads (see Table 1 for participant characteristics).

One or both parents completed the parental questionnaire. No additional information on the background of the parents is available.

Participants lived in the Netherlands or Belgium. In general the population of both countries has a liberal attitude to adolescent sexuality (de Looze, Constantine, Jerman, Vermeulen-Smit, & Ter Bogt, 2014), meaning that parents think about adolescent sexuality as a normative activity in romantic relationships. Comprehensive sex education is part of most school curricula.

Materials

Self-report data

All boys answered nine questions on lifetime experience of romantic relationships and common solo and partnered sexual behaviours (Fortenberry, 2013b; Moore & Rosenthal, 2006). These questions were part of an online questionnaire developed for the 'Sex under

Table 1. Sample characteristics (*N* = 43)

	***M* (*SD*) (Range)**	***n***	**%**
Age	16.67 (.81) (Range: 15-18 years)		
Primary diagnosis (DSM IV-TR)			
- Autistic Disorder		18	42
- Asperger's Syndrome		25	58
ADOS module 4 (*n*=41)	8,29 (2,9) (Range: 3-14)		
- Above cut-off Autism		16	37.2
- Above cut-off Autism Spectrum		14	32.6
- Below cut-off Autism Spectrum		11	25.6
Comorbidity			
- Attention Deficit Disorders		12	28
- Anxiety Disorders		3	7
- Learning Disorders		3	7
Full Scale IQ (*n*=39)	104.26 (15.87) (Range: 76 – 142)		
Educational level			
- Low (secondary education, prevocational level and lower)		26	60
- High secondary education		17	40

the age of 25 II' study (de Graaf et al., 2012). This questionnaire consisted of 177 questions relating to various aspects of sexual health. All nine questions followed a closed, multiple-choice answer format. The questions were formulated in simple language ('Have you ever…') and the relevant sexual behaviours were described in discrete boxes placed next to the questions. The response format for all questions was dichotomous (yes/no), except for the question on experience of orgasm (third alternative: I don't know).

Parent reports

Parents answered nine questions about their sons' lifetime experience of various sexual behaviours, which were developed specifically for this study. The self-report questions on common sexual behaviours were adapted to be completed by parents ('did your son ever…' instead of 'did you ever…'). All questions followed a closed, three-choice (yes; no; don't know) format.

Procedure

Following ethical review (Medical Ethical Committee reference NL34563.097.11 in the Netherlands; approval 4112 by the Institutional Review Board ZNA/OCMW in Antwerp, Belgium) participants were recruited from several institutions and schools between January 2012 and May 2013. Eligible participants and their parents received an information letter and leaflets on the study from the organisations and professionals working with them. None

of the participants was dependent on the researchers for treatment. Parents and adolescents were invited to contact the researcher to indicate whether they were willing to participate. If no response was received within 10 days they were contacted again. A call for participants was also posted on the website of the Dutch Autism Association. All participating boys and parents gave written informed consent.

The participating boys could complete the online questionnaire in private and anonymously in whatever location they found convenient (at school; at home or another residence; at our centre); most chose to complete the questionnaire with a researcher nearby to answer questions if necessary. The researcher could not see the boys' answers during completion. Some boys asked for help or preferred to have the questions read aloud by the researcher. Two boys preferred to complete the survey on their own at home. Participants received a €5 voucher after completing the survey. If possible, the ADOS was conducted in the same session, before the boy completed the questionnaire.

Parents could complete the parental questionnaire online at a secured webpage or in a paper-and-pencil version.

Statistical Analysis

We report the number of adolescents who confirmed the different sexual experiences, agreement between parents and their sons separately on the occurrence and non-occurrence of the lifetime sexual experience, the proportion of parents who were ignorant of whether their son had or had not experienced each form of sexual behaviour, and parental awareness (sum of agreement on occurrence and non-occurrence). SPSS21 was used for data analysis.

The collected data were not suitable for further statistical analyses. The reported percentages do offer insight into differences between parent- and self-report.

RESULTS

As can be seen from Table 2, half of the parents reported that they did not know whether their sons had experienced masturbation or orgasm.

Almost all boys reported that they had masturbated and the majority had experienced orgasm. About half the parents of adolescents who had solo sexual experience were aware of this. The majority of parents correctly reported that their son had had a relationship and or had experienced French kissing. About a third of the boys reported that they had had sexual intercourse with a girl. A quarter of the parents stated that they did not know if their son had experienced sexual intercourse. Eight out of 12 parents reported correctly that their son had had intercourse. The majority of parents reported same sex experience or

Table 2. Agreement on sexual experience between boys with ASD and their parents (*N* = 43 dyads)

Relational or sexual behaviour	Adolescent report		Parental report						Parental Awareness[1]	
			Agreement on occurrence		Agreement on non-occurrence		Do not know			
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
Masturbation	41	95.3	22	53.6	1	50	19	44.2	23	53.5
Orgasm	38	88.4	19	50	1	100	22	51.2	20	46.5
Relationship	32	74.4	28	87.5	10	91	1	2.3	38	88.4
French kissing	26	60.5	20	76.9	12	71	7	16.3	32	74.4
Petting above clothes	24	55.8	16	66.6	12	63	11	25.6	28	65.1
Penile/vaginal intercourse	12	27.9	8	66.7	22	71	12	27.9	30	69.8
Making love to a boy	1	2.3	0	0	39	93	3	7	39	90.7
Forcing someone else to do sexual things	2	4.7	1	50	35	85	7	16.3	36	83.7
Being forced to do sexual things	3	7	1	33.3	37	92	1	2.3	38	88.4

[1] Parents correctly aware of the presence or absence of sexual behaviour

lack thereof correctly. Overestimation by parents (i.e. false positives) was rare: two parents assumed incorrectly that their sons had experience with kissing, and one parent thought this about hugging. One in six parents stated that they did not know whether or not their son had forced someone to do sexual things, and most parents thought that their son had not suffered sexual victimisation. Only a small percentage of boys reported same-sex sexual experiences, sexual victimisation, or sexual coercion. Not all parents knew about of their sons' negative sexual experiences (coercion and victimisation).

DISCUSSION

This study investigated agreement between parental and self-report on the lifetime sexual experience with common solo and partnered sexual acts in adolescent boys with ASD. The results confirm that boys with ASD report more sexual experience than their parents are aware of. Overall, a substantial proportion of parents was uncertain about the extent of their son's sexual experiences or underestimated their son's sexual experience, particularly with respect to solo sexual behaviours. There is no evidence that parents of adolescents with ASD differ from those of boys in the general population pertaining to their awareness of the sexual experience of their children. However, our insight in sexual functioning of adolescents with ASD is mostly based on parental, teacher, and caregiver reports (e.g. Hellemans et al.,

2007; 2010; Mehzabin & Stokes, 2011; Stokes & Kaur, 2005) and might thus be biased. The results of this study have not only implications for the interpretation of earlier research but also for sex education.

Parents were less likely to report that they knew about their sons' solo sexual experiences (masturbation; experiencing an orgasm) than about their partnered sexual behaviours (having been in a relationship; penile-vaginal intercourse). Parents often declared that they were uncertain about whether their sons masturbated, rather than incorrectly assuming that they did not. Parents' uncertainty about their sons' masturbation habits might indicate that these adolescents masturbated in private, as is socially appropriate. Masturbation plays an important role in the sexual development of boys (Robbins et al., 2011) and is one of the most common and earliest sexual experiences in male adolescent sexual development; low levels of parental knowledge about masturbation habits might reflect limited parent-adolescent discussion about masturbation. For many people, there is a taboo on talking about masturbation because of its undeniably sexual connotation. Frankel (2002) argued that parents were less inclined to discuss semenarche (first ejaculation) with their sons than menarche with their daughters due to the sexual connotations of semenarche. Although semenarche should not be confounded with masturbation it is possible that similar taboos influence parental discussion of both topics. Partnered sexual behaviours are possibly easier to discuss, because they can be related to safe sex and prevention of teenage pregnancy, i.e. discussed as a health issue rather than as a sex issue. Masturbation is more directly related to sexual pleasure. It might be valuable to offer adolescents boys with ASD timely and appropriate information about sexual arousal, sexual pleasure, and masturbation to support their sexual development. Holmes & Himle (2014) found that many parents did not discuss general aspects of sexuality and relationships, apart from issues related to abuse prevention, hygiene and privacy. Unfortunately our data do not reveal whether or not the parents in this study discussed these topics with their sons. The role of parent-adolescent communication about sex in the sexual development of adolescents with ASD is a subject for further research. Also, the data do not offer insight in the way the boys deal with masturbation. We do not know if there is a relationship between inappropriate masturbation practices and the awareness of parents.

Parent-adolescent agreement about sexual experiences was higher with respect to romantic relationships and partnered sexual experiences than solo sexual experiences. The majority of the boys with ASD in this study had been in a romantic relationship, and most parents were aware of this; nevertheless about a third of parents underestimated their sons' partnered sexual experience. The underestimation of sexual experience of their sons' might reflect limited discussion of sexual experiences between adolescents and parents. It is also possible that assumptions about their sons' lack of sexual experience temper parents'

inclination to discuss partnered sexual behaviours with their sons. The taboo on discussing romantic relationships is possibly less strong than the taboo on talking about the sexual aspects of relationships. The higher level of agreement about partnered sexual experience might also be explained by the generally lower frequencies of partnered experiences. Given parental underestimation, the probability of agreement on the absence of a behaviour is higher in the case of low-frequency behaviours (Mollborn & Everett, 2010). It would be interesting to examine parent-adolescent agreement on the partnered sexual experiences of older boys with ASD as it is possible that a higher proportion of them will have had partnered sexual experiences.

The number of boys who reported having forced someone else to do sexual things or having been forced to do sexual things themselves was low. Slightly more parents stated that they did not know if their son had coerced someone into sexual behaviour than reported that they did not know if their son had been victimised sexually. This finding should be interpreted with care, given the exploratory nature of this study; however parents could have doubted about the possibility that their sons coerced others to sexual behaviours.

Earlier research (Ballan, 2012; Nichols & Blakeley-Smith, 2009) suggested that parents do not know what to expect when it comes to the sexual development of adolescent children with ASD and hesitate to discuss issues related to sex and sexuality when they are unsure whether the adolescent has any sexual interest. It is possible that adolescents react negatively or hesitantly when their parents initiate discussions about sex and sexuality and this might further enhance parents' uncertainty about how to handle the issue. Given that only limited evidence is available on the sexual development of children and adolescents with ASD, the underestimation of sexual experience seen in this study might be related to a lack of sex communication and education among a significant proportion of adolescents with ASD. Research evidence and clinical opinion agree that sex education delivered by parents is important (Ballan, 2012; Hellemans et al., 2007; Mehzabin & Stokes, 2011; Nichols & Blakeley-Smith, 2009; Stokes & Kaur, 2005), so it is advisable to help parents fulfil this duty by providing information appropriate to the age and physical maturity of their child. There is still no systematic evidence about the prevalence of abnormal sexual development in adolescents with ASD; it is therefore possible that features of ASD might increase the probability of a child finding the physical changes and development of sexual interest associated with sexual maturation a negative experience. Similarly, features of ASD may increase the risk of developing inappropriate sexual behaviours. In daily clinical practice we meet adolescents who develop specific, sometimes inadequate, masturbation techniques or paraphilic arousal patterns that cause concern when they come to light. There is also no evidence on the prevalence of paraphilias or problems with masturbation in boys with ASD; however early and sensitive attention to sexual arousal and masturbation may promote healthy sexual development. It might be a challenge for parents

to understand and discuss sexuality development in adolescent with ASD, and to deal with seemingly inappropriate sexual behaviours. Hence, professional support and information should be available for parents.

Finally, parents' underestimation and ignorance of the extent of the lifetime sexual experience of adolescent sons with ASD has implications for the interpretation of research based on parent or caregiver reports. Future research on sexuality in people with ASD should include self-report data in order to get more insight into development in this domain. Additional research based on self-report data could improve our understanding of sexual development in adolescents with ASD.

Strengths, limitations, and further research

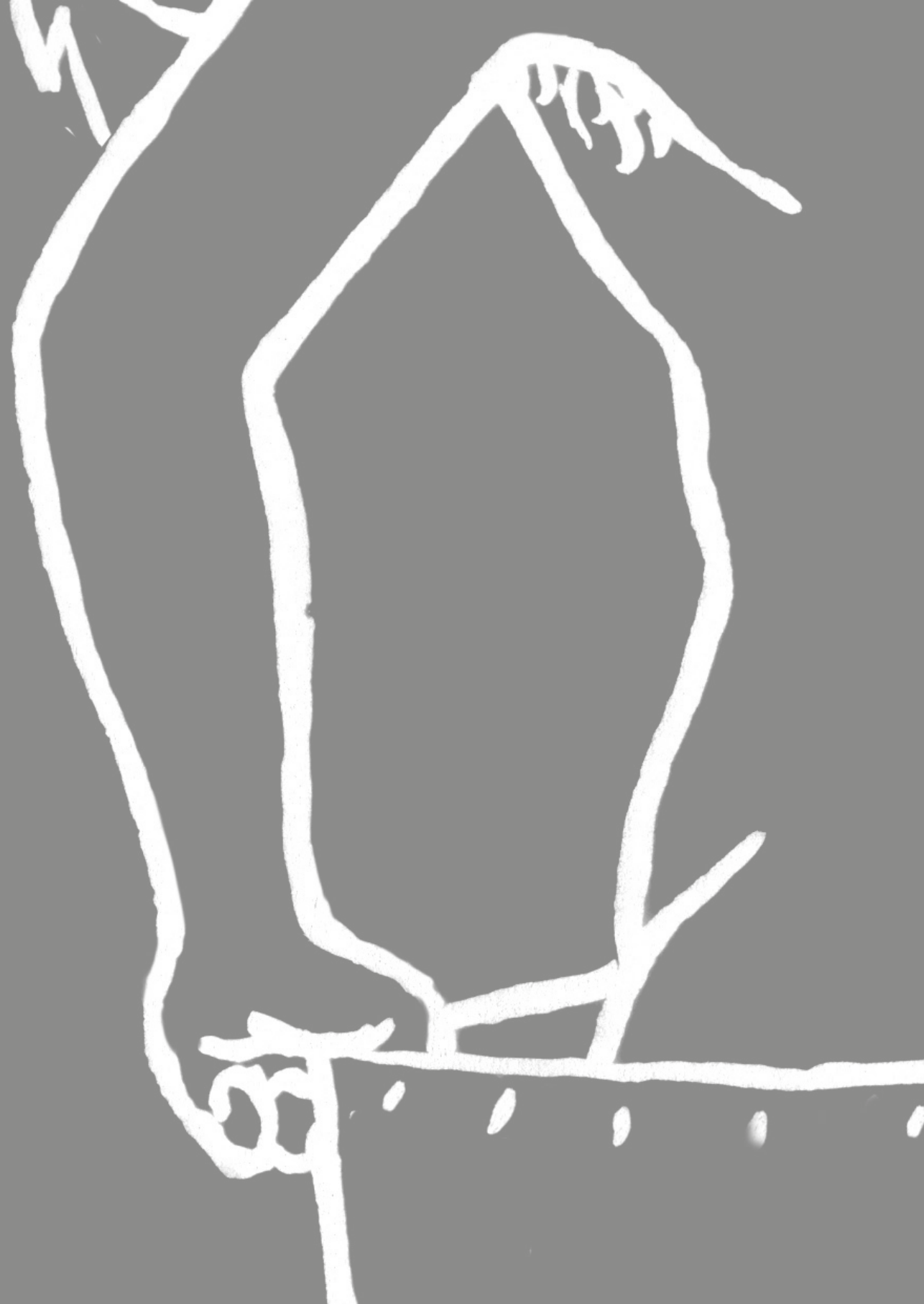
This is the first comparison of parental reports and self-reports of the lifetime sexual experience of boys with ASD in a sample of parent-child dyads and provides additional insight into earlier studies based on parent and caregiver reports of sexual behaviours in adolescents with ASD. Nevertheless the limitations of the study should be borne in mind. First, possible selection bias and the participant profile (the sample was limited to adolescents with high-functioning autism) limit the generalizability of our findings. Second, it has been reported that mothers and fathers communicate differently about sex and sexuality with their children (Diiorio, Pluhar, & Belcher, et al., 2003) and we do not have data on which parent or parents completed the questions about adolescent sexual experience in our study. Third, this study only focused on lifetime experience with the most common solo and partnered sexual acts, leaving questions on different other aspects relating to sexuality still unanswered.

Our results and the limitations of the study raise issues for further research. First, this study should be replicated in other samples of adolescent boys and girls with ASD to confirm and refine our findings. In addition, further research should look for behavioural cues to detect adolescents' problems or concerns about sex and sexuality, which should trigger additional support or early intervention. Finally, little is known about the variables, for instance parent-child communication about sex and sexuality, which influence parental awareness of the sexual behaviour of adolescents with ASD.

CONCLUSION

Parents play a critical role in education about sex and sexuality, although they are often uncertain about how, when and what information to provide or discuss (Ballan, 2012; Holmes & Himle, 2014; Nichols & Blakeley-Smith, 2009). Comprehensive sex education, including a

variety of issues relating to sexuality including solo and partnered sex (SIECUS, 2004) is likely to play an important role in promoting healthy sexual development and preventing harmful or aversive sexual experiences in adolescents with ASD, as it does in other adolescents. Several authors (e.g. Attwood et al., 2014; Dekker, van der Vegt, et al. , 2015; Hénault, 2005) made suggestions on sexuality education and developed programs attuned to adolescents with ASD. This study showed that parents tend to be uncertain about, or underestimate the extent of their adolescent's sexual experience; this suggests they would benefit from receiving information about sexual development in adolescents with ASD. Such information should be made more available and parents should also have access to support to help them make decisions about when and how to discuss issues of sex and sexuality.



CHAPTER 4

Adolescent boys with Autism Spectrum Disorder growing up: Follow-up of self-reported sexual experience

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ABSTRACT

Systematic research on sexual development in adolescents with Autism Spectrum Disorder (ASD) remains scant, notwithstanding the often-suggested relation between ASD, atypical and even sexually offensive behaviours. This study compared follow-up data related to lifetime sexual experience (LTSE) in a homogeneous group of adolescent boys with ASD (*n*=30), aged 16-20, with a matched group of boys in the general population (*n*=60). Most boys in the ASD and control groups reported masturbation and having experienced an orgasm. The proportion of boys with ASD that had no partnered sexual experience was larger than in the control group. This difference was mostly explained by significantly fewer boys with ASD, compared with controls, who reported experience with kissing and petting; no significant differences emerged relating to more intimate partnered sexual experiences. The results suggest the existence of a subgroup of boys who have not (yet) entered the arena of partnered sexual experiences – a finding in line with research in adult samples. There were no differences relating to sexual abuse or coercion. Exploration of the partnered experiences revealed a variety of types of partners, mostly of comparable age. Several boys with ASD had not anticipated their sexual debut. Although they felt ready for it, some boys reported regret afterward. The hypothesised sexual developmental trajectories are subject to further research, but the sexual experience in this sample and the assumed developmental differences indicate the need for early, attuned and comprehensive sexuality-related education and communication.

Keywords: Autism Spectrum Disorders; Sexuality; Sexual Behaviour; Adolescence.

INTRODUCTION

Recent research on sexuality in high-functioning adolescents and adults with Autism Spectrum Disorder (ASD) refutes old assumptions regarding the absence of sexual interest and sexual experience in this group and counters problematising views on their sexuality (Byers et al., 2013, 2012; Byers & Nichols, 2014; Dewinter et al., 2015). Notwithstanding these results, other studies (Dekker, Hartman, et al., 2015; Ginevra, Nota, & Stokes, 2015; Hellemans et al., 2007, 2010; Stokes et al., 2007; Stokes & Kaur, 2005), clinical observations and case studies demonstrate that healthy sexual functioning, as defined by the World Health Organisation (2006), is a challenge for some adolescents and adults with ASD (Dewinter et al., 2013; Kellaher, 2015). Empirical and case studies pertaining to individuals with different levels of cognitive functioning levels describe a variety of atypical or inappropriate sexual behaviours and interests. Moreover, problems related to sexual functioning, such as showing genitals and masturbation in public, fetishism and offending, are mentioned (for an overview see (Dewinter et al., 2013; Kellaher, 2015)). Gender identity issues in individuals with ASD are also reported (de Vries et al., 2010; Gallucci et al., 2005; Jacobs, Rachlin, Erickson-Schroth, & Janssen, 2014; Kraemer, Delsignore, Gundelfinger, Schnyder, & Hepp, 2005; Landén & Rasmussen, 1997; Lemaire, Thomazeau, & Bonnet-Brilhault, 2014; Mukaddes, 2002; Perera et al., 2003; Schalkwyk, Klingensmith, & Volkmar, 2015; Tateno, Tateno, & Saito, 2008; Williams, Allard, & Sears, 1996). However, studies on ASD and sexuality are characterised by a variety of methodological limitations relating to the participant characteristics (different levels of cognitive functioning, different operationalisations of ASD, mixed sex groups), research methods (self vs. parent or third-party reports), absence of control groups, and limited sample sizes, which makes it difficult to generalise the results. Notwithstanding the methodological problems and inconclusive findings, the social, communicative, and repetitive behaviours and interests characterising ASD (APA, 2000) could explain the emergence of some sexuality-related problems. Additionally, secondary aspects relating to ASD, such as the environment where adolescents with ASD live and are raised (e.g., single sex group homes vs. at home) (Hellemans et al., 2007), access to sexuality education (Dekker, Vegt, et al., 2015), and the pharmacological treatment they receive (Roke et al., 2012), may influence sexual development. Thus, characterising the relation between sexuality development and ASD is warranted in order to learn what support is needed to promote sexual health in people with ASD.

Sexuality development gains momentum during adolescence after sexual maturation related to puberty. Over the past several years, a normative view on adolescent sexual development has been widely accepted (Tolman & McClelland, 2011): the problematising views on adolescent sexual development (e.g., focus on sexually transmittable infections

(STIs) and teen pregnancies) have been replaced by the idea that sexuality is a normal and positive aspect of adolescent functioning (O'Sullivan & Thompson, 2014). However, research on normative sexual development in adolescents with ASD is scant (Dewinter et al., 2013; Kellaher, 2015). Although longitudinal studies are important sources of information on sexual development, to date these are scarce in adolescents with ASD. All existing studies on sexuality and ASD are cross-sectional, except one (Dekker, Hartman, et al., 2015). Three studies controlled for the influence of age. Byers and colleagues (Byers et al., 2012) found no relation between the age of their adult participants (age range 21-73) and their sexual well-being. Similarly, in the study by Stokes and Kaur (Stokes & Kaur, 2005), no differences emerged in the relation between age (age range 10-15) and sexually inappropriate behaviours in the comparison of the ASD and control samples. In a recent study, Ginevra and colleagues (Ginevra et al., 2015) found more inappropriate sexual behaviours in adolescents with ASD compared with general population controls and youths with Down's syndrome, independent of their age. In their longitudinal study, Dekker and colleagues (2015) found an association between autistic traits in children at age 10-12 and parent-reported sexual problems in early adolescence (age 12-15). Although these studies offer insight into sexual functioning of adolescents and adults with ASD, they provide little information regarding sexual development and sexual experience over time in adolescence. Taken together, although the number of studies on sexual development in individuals with ASD is growing, and notwithstanding that there is increasing attention to different issues relating to sexual well-being, several questions relating to sexuality development in ASD remain, e.g., regarding factors that promote healthy sexual development, or that predict sexual problems. In general, the insight into sexual development in adolescents with ASD is only emerging, and the results need further corroboration.

In 2012-2013, the self-reported lifetime sexual experience (LTSE) in a homogeneous sample of high-functioning adolescent boys with ASD was compared with a matched control group of general population boys. The LTSE in the boys with ASD did not differ from that of controls in 2012-2013 (Dewinter et al., 2015). The aim of the present follow-up study was to compare the LTSE in this group of high-functioning boys with ASD to a matched control group two years after the initial assessment. In order to characterise the sexual development in boys with ASD, the first goal was to compare solo, partnered and online sexual behaviours with a general population-matched control group. Second, the change in sexual experience over the last two years within the ASD group was inventoried. A substantial number of boys in the general population gain partnered sexual experience between age 16 and 20 (de Graaf et al., 2012; Fortenberry, 2013b). Finally, additional information on partnered sexual experiences of the boys with ASD was explored.

METHODS

Participants

All eligible candidates participated in an earlier study on sexual functioning in adolescent boys with ASD (*n*=51) (Dewinter et al., 2015) and agreed to be contacted again to participate in follow-up studies (*n*=43 of the 51 original participants). Thirty boys (age *M*=18.62, *SD*=.96, range16.64-20.29) of the original sample agreed to participate in the present study (see Table 1).

Table 1. Participant characteristics

			n	*(%)*
			(*N*=30)	
ASD	Autistic Disorder		14	(46.7%)
	Asperger's Disorder		16	(53.3%)
ADOS module 4	Above Autism cut-off		9	(30%)
	Above ASD cut-off		9	(30%)
	Below cut-off		12	(40%)
Living situation	Home		23	(76.7%)
	Living independently		5	(16.7%)
	Group home		1	(3.3%)
	Residential psychiatric treatment		1	(3.3%)
Educational level	High		11	(36.7%)
	Low		19	(63.3%)
Intelligence (Full scale IQ) (n=29)[1]	(*M*=108.07, *SD*=14.4, *range*=76-142)			
	Very superior	130+	1	(3.4%)
	Superior	120-129	6	(20.6%)
	High average	110-119	6	(20.6%)
	Average	90-109	14	(48.2%)
	Below average	80-89	1	(3.4%)
	Borderline	70-79	1	(3.4%)

[1]One missing, functioning on higher-prevocational level

Participants were Dutch or Belgian boys, diagnosed with Autistic Disorder or Asperger's disorder (APA, 2000) by mental health professionals. All participants were high-functioning (Bölte, 2014); they attended regular classes or scored in the borderline-to-higher range on a standardised intelligence measure (Full Scale IQ 76-142). Florid psychotic symptomatology was the only exclusion criterion. No evidence for attrition bias was found. The participating (*n*=30) and non-participating (*n*=21) boys had comparable ages at t1 (M_{part}=16.6, *SE*=.*16*, M_{non-}

$_{part}$=16.7, *SE*=.14, *t*(49)=.522 *p*=.604, *r*=.07), educational level (high vs. low (i.e., prevocational), χ^2(1)=.612, *p*=.565, *V*=.11), and diagnosis (Autistic disorder vs. Asperger's Disorder, χ^2(1)=.907, *p*=.397, *V*=.13). Both groups (M_{part}=7.5, *SE*=.73, $M_{non\text{-}part}$=7.8, *SE*=.83, *t*(49)=.276, *p*=.783, *r*=.04) had comparable Autism Diagnostic Observation Schedule (ADOS) module 4 scores. Participants (*Mdn*=2, range 0-9) and non-participants (*Mdn*=3, range 0-8) did not differ regarding their LTSE at the first assessment (2012-2013) (*U*=314, *z*=-.20, *p*=.988, *r*=-.028). No differences emerged between both groups relating to specific solo (masturbation) and partnered (kissing, petting, manual, oral, penile-vaginal and anal sex) experiences on item level.

The participant group was matched to a general population control group (*M*=18.63, *SD*=1.09, range 16.02-20.77). Control data were selected out of a large database (data from 3926 boys and 3915 girls, living in the Netherlands, aged 12 to 25) collected for a nationwide study, 'Sex under the age of 25 II', on sexual health in adolescents in the Netherlands (de Graaf et al., 2012), kindly provided by the authors. Recruitment of the participants in the population study took place through schools and Municipal Administrative Systems. The control group consisted of 60 participants, matched to the participant group based on age, educational level (low/high), living area (Southern-western region of the Netherlands), and sex (male). A stratification procedure was used, and the maximal possible control group was selected. Information on intelligence scores and psychopathology in the control group was not available. The participants in the control group in the present study differ from those in Dewinter et al. (2015): no follow-up data of the controls are available.

Materials

Sexuality

The participants completed a shortened version of the computerised online survey developed for the 'Sex under the age of 25 II' study (de Graaf et al., 2012). The questionnaire for the present study consisted of 105 items. The original questionnaire had 172 items: questions that did not pertain to the focus of the present study were deleted. Participants were not obliged to answer all the questions: only those items that applied to them (e.g., boys did not receive questions about pregnancy) were hierarchically selected (e.g., if a respondent confirmed having been in a relationship, other questions relating to relationships were offered). All questions were formulated in an easy and straightforward way (see Appendix 1) and had a closed multiple choice answer format. Specific terminology (e.g., masturbation) was explained next to each question. All questions have good face validity. One scale, LTSE, was calculated (Cronbach's alpha based on standardised items α=.907 in the present sample) consisting of nine questions pertaining to the most common solo (masturbation) and partnered sexual experiences (French kissing (or tongue kissing), petting (referring to caressing or fondling with clothes on), masturbating another, being

masturbated, passive oral sex, active oral sex, penile-vaginal sexual intercourse, and anal sex). All other comparisons were carried out on item-level. Details about the construction of the original questionnaire can be found in the study by De Graaf and colleagues (de Graaf et al., 2012).

ASD

All participants had been diagnosed with Autistic Disorder or Asperger's Disorder (APA, 2000) before inclusion in this study. The ADOS, fluent speech module (4) (Lord et al., 2012), was used to assess ASD characteristics in the participants. The ADOS is considered to be part of the gold standard in ASD diagnostics (Falkmer, Anderson, Falkmer, & Horlin, 2013). The first author, qualified to use the ADOS for research purposes, conducted all assessments.

Procedure

After approval of this study by the Medical Ethical Committee Brabant, Tilburg, the Netherlands (NL49082.028.14), the first author contacted all eligible participants by e-mail or phone. The participants indicated earlier whether and how they could be contacted again. All boys received extensive information (a general invitational mail containing a leaflet on the background of this study, ethical considerations, voluntariness, the possibility to withdraw, privacy issues, the way of reporting and the possibility to gain independent advice or file complaints) regarding the study, and an informed consent document they could send back to the researcher when they agreed to participate. The parents of underage boys (< age 18) also gave written consent. The boys received a link to the online questionnaire and a neutral personal user name and password. The participants could log in and out, and did not have to complete the questionnaire in one sitting; they were asked to answer the questions within two weeks. The first author monitored whether the questionnaires were completed, and sent an additional e-mail after two weeks to yet again invite the participants to complete the questionnaire. One boy agreed to participate but did not fill in the questionnaire and indicated that he was too busy. During data collection, the results were stored on a secured server. The boys could indicate if they wanted to complete the questionnaire on their own or in the presence of the first author. Only one boy preferred the presence of the researcher. The boys could contact the researcher in case they had questions relating to the questionnaire or the topic. All boys received a voucher (5€) after participation.

Statistical analysis

The main goal of this study was to compare frequencies and means relating to experience with different sexual behaviours in the participant group compared with the general population control group. Chi-square (χ^2, 2 by 2) tests were used to compare frequencies

pertaining to item-responses. Two-tailed probabilities and Cramer's *V,* as the effect size (*V*=.30 medium effect size, *V*=.50 large effect size (Cohen, 1988)), were reported. Fisher's exact test was applied when the cell frequencies were expected to be below five. Mann-Whitney (*U*) was used to compare medians and distribution of the LTSE scale, given the non-normally distributed data. Exact two-tailed probabilities were reported. The reported effect size was *r* (.>50 indicates a large effect). Kendall's tau (τ) was applied to check the correlations between non-normally distributed data. In order to explore the change in sexual experience, the order in which sexual behaviours were acquired was studied. Mokken scale analysis was performed in R (https://www.r-project.org) to evaluate Guttman characteristics of the LTSE scale. Loevinger's *H* was reported (maximal value *H*=1). No statistical testing was performed on subgroups, given the small samples sizes.

A priori power analysis (α=.05, 1-β=.80) using G*power (Faul, Erdfelder, Lang, & Buchner, 2007) demonstrated that medium to large effect sizes (*w*>.03) could be detected in a total sample of *n*=88. This sample also allowed finding large effects (*d*=.8) when applying 2-tailed *t*-tests or non-parametric alternatives. Repeated testing in the same group increases the risk for type I errors. Given the signalling function of an explorative study, we decided to keep α=.05 and to report effect-sizes. SPSS 19 was used for data analysis.

RESULTS

Sexual experience in 2014: ASD vs. controls

The ASD and control group did not differ in the percentages of boys who had experience with masturbation, and reported having had an orgasm (see Table 2).

However, a few more participants with ASD had no partnered sexual experience compared with controls (Fisher's exact *p*=.012, Cramer's *V*=.282). On an item level, only significant differences existed relating to French kissing and petting. Differences pertaining to other partnered experiences were non-significant and small. Boys in both groups reported similar ages of first experience with each of the listed sexual behaviours. LTSE (9 items) proved to be a Guttman scale (scale Loevinger's *H*=.949), i.e., items could be hierarchically ordered: (1) masturbating, (2) French kissing, (3) petting, (4-6) being masturbated, receiving oral sex, sexual intercourse, (7) masturbating another, (8) oral sex to another, and (9) anal sex. A participant who scored on a specific item also scored on all subsequent items. Comparison of scale scores between both groups revealed no significant difference between the ASD group (*Mdn*=7, *M*=5.2) and controls (*Mdn*= 8, *M*=6.28, *U*=716, *z*=-1.638, *p*=.103, *r*=-.173). The correlation between LTSE, age (τ=-.042, *p*=.763), and the total ADOS score (τ=.006, *p*=.970) was low.

Table 2. Lifetime sexual experience 2014

	Lifetime experience					Age first time[4]				
	ASD *n(%)* (*N*=30)	Control *n(%)* (*N*=60)	X^2 (df=1)	*p*	Cramer's *V*	ASD *Mdn*	Control *Mdn*	*U*	*z*	*p*
Has been in love	24 (80)	57 (95)	n/a	.055[1]	.236	n/a	n/a	n/a	n/a	n/a
Dating	20 (66.7)	51 (85)	4.04	.057	.212	15	15.5	368.5	-1.839	.066
Masturbation	29 (96.7)	54 (90)	n/a	.417[1]	.117	13.5	13.5	714	-.677	.503
Orgasm	28 (93.3)	56 (93.3)	.00	1.00	.000	13.5	13.5	684	-.969	.336
Partnered sexual experience	21 (70)	55 (91.7)	n/a	.012	.282	n/a	n/a	n/a	n/a	n/a
French kissing	21 (70)	53 (88.3)	4.6	.042	.226	13.5	13.5	485	-.865	.391
Petting with clothes on	21 (70)	53 (88.3)	4.6	.042	.226	15.5	15.5	500	-.691	.494
Masturbating another	16 (53.3)	45 (75)	4.29	.055	.219	16	15.5	349.5	-.177	.864
Being masturbated	17 (56.7)	43 (71.7)	2.02	.235	.150	16.5	15.5	365	-.008	.997
Oral sex[2] (active)	15 (50)	38 (63.3)	1.469	.261	.128	16.5	16.5	271	-.284	.784
Oral sex[2] (passive) (n=21)	17 (56.7)	39 (65)	.591	.494	.081	16.5	16.5	323.5	-.147	.886
Penile-vaginal intercourse	17 (56.7)	40 (66.7)	.861	.487	.098	16.5	16.5	315	-.450	.659
Anal sex[2]	3 (10)	12 (20)	1.44	.369	.126	17.5	17.5	15.5	-.368	.824

[1]Fisher's exact, [2]question only asked in case of other partnered experience (ASD *n*=21, contr. *n*=55)

The control and ASD groups did not differ regarding the proportion of boys that used the internet for sexuality-related means (see Table 3). A substantial number of the boys without partnered experience in both groups did watch porn but did not use the internet for other sexuality-related means. The boys with ASD who used the internet for other sexuality-related means (chatting about sex, sending pictures) mostly had experience with a partner.

Sexual development in boys with ASD

The time between the first assessment (Dewinter et al., 2015) and the completion of the questionnaire for the present study was on average 2.02 years (*SD*=.46). Given that the LTSE was a Guttman scale, the change in LTSE between the first assessment and follow-up could be compared. The majority of the participants without partnered experience at the first assessment did not gain experience at follow-up. Table 4 shows the change in sexual experience between the first assessment in 2012-2013 (t1) (Dewinter et al., 2015) and the present.

Table 3. Online sexual activity

	ASD *n* (%)	Controls *n* (%)	X^2 (df=1)	*p*	Cramer's *V*	Partnered experience yes (*n*=21)	Partnered experience no (*n*=9)
Talking about sex	12 (40)	23 (38.3)	.023	1.00	.016	11	1
Flirting	13 (43)	27 (45)	.023	1.00	.016	12	1
Showing genitals or buttocks	3 (10)	4 (6.7)	n/a	.682[1]	.059	3	0
Posting images of yourself	3 (10)	2 (3.3)	n/a	.328[1]	.137	3	0
Sex with someone met on the internet	2 (6.7)	3 (5)	n/a	1.00[1]	.034	2	0
Watching porn	25 (83.3)	47 (78.3)	.313	.781	.059	19	6

[1]Fisher's exact

Two boys with ASD had no sexual experience at all at t1, and one of them gained experience with masturbation in 2014. Three boys who had only solo sexual experience at t1 reported partnered experience at follow-up, and two boys who had been kissing and petting gained more intimate sexual experience at follow-up. Only eight out of 30 boys moved to a next level of sexual experience. At follow-up, still fewer boys with ASD had experience with French kissing and petting, the most common first partnered experiences, compared to boys in the control group, indicating that they did not take the next step in gaining sexual experience. Most boys who reported partnered experience at an earlier age evolved to more intimate sexual behaviours (manual or oral stimulation, and sexual intercourse).

Table 4. Sexual development

N=30	t1 (*n*)	change between t1 – t2 (*n*)		t2 (*n*)
No experience (NE)	2	no change	1	1
Solo experience (SE)	11	NE t1 - SE t2	1	8
		no change	7	
Kissing & petting (KP)	5	SE t1 - KP T2	1	3
		no change	2	
Intimate sexual experience (ISE)	12	SE t1 - ISE t2	3	18
		KP t1 - ISE t2	3	
		no change	12	

Explorative findings relating to partnered sexual experience in the boys with ASD

Two boys with ASD reported to be forced to do sexual things against their will, compared with none in the control group. Three boys indicated having sexually coerced another, as did two boys in the control group. One boy with ASD had sexual intercourse with a professional sex-worker and had been paid himself to have sexual contact. About half the boys with ASD

who had experience with sexual intercourse (*n*=17) had two or more different sex partners (M_{ASD}=3.41, M_{contr}=2.28). Fourteen of these boys had followed a linear developmental trajectory (de Graaf, Vanwesenbeeck, Meijer, Woertman, & Meeus, 2009): they had experience with less intimate behaviours (kissing, petting) at least one year (*M*=2.18, *SD*=1.47) before they had more intimate experiences (oral and manual stimulation of or by the partner, sexual intercourse). Eleven boys (64.7%) used a condom when they first had sex, comparable to the rate in the control group (77.5%). About half the boys with ASD who had experience with sexual intercourse (ASD 52.9%, controls 80%) indicated they liked their first time having sexual intercourse, and six (35.3% of the experienced boys with ASD, 12.5% of controls) of them preferred it to have happened earlier. For about half of the boys with ASD (ASD 52.9%, controls 20%), the timing of their first experience having sex was unexpected. One boy indicated that he did not like his first time having sexual intercourse. After their first-time sexual intercourse, 41.2% had regrets afterwards, compared to 7.5% of controls. Most boys had same-aged partners (ASD 58.8%, controls 76.2%), and some had at least two-year-older partners (ASD 17.6% vs. controls 7.5%). The type of relationship with the sex partners was comparable in both groups: a romantic relationship (ASD 64.7%, controls 65%), a summer love (ASD 11.8%, controls 10%), or someone else (ASD 23.5%, controls 25%). In this study, only one boy with ASD had sexual experience with another boy, and one other indicated interest.

DISCUSSION

This study helps to elucidate the sexual development of high-functioning boys with ASD compared with general population peers. The results confirm that sexuality is part of adolescent development in boys with ASD, as it is for their peers. However, some differences pertaining to sexual experiences with a partner emerged between boys with ASD and the controls.

Common sexual experiences in boys with ASD

Almost all boys, ASD and controls, reported having masturbated and had experienced an orgasm. The majority had some partnered sexual experience; however, fewer boys with ASD had partnered sexual experience compared with boys in the general population. This difference between boys with ASD and controls relating to partnered experience was not found two years prior (Dewinter et al., 2015). The differences pertained to the lower number of boys with ASD who gained experience with French kissing and petting. All frequencies relating to partnered sexual behaviours seemed to be lower in the ASD group, compared

with the control group; however, most of these differences did not reach significance, and most effect sizes remained small. In general, these results demonstrate the normativity of sexuality in the development of boys with ASD.

ASD and sexual development

Within the group of boys with ASD, no relation between sexual experiences and the amount or severity of ASD features could be detected. However, LTSE, or having sexual experience, offers little insight as to the quality or context of these experiences: it might be possible that ASD features have some influence on the type or duration of romantic and sexual experiences. The absence of a relationship between ASD severity and LTSE in this study probably indicates that the majority of boys with ASD are interested in sexuality and partnered experiences. However, methodological issues, such as the sensitivity of ADOS as a measure for ASD-severity (ADOS), might also explain the absence of a relation.

The exploration of the individual developmental trajectories of the boys with ASD revealed that boys with more intimate partnered experience also had experience with all less intimate behaviours and masturbation. It should be noted that, in this study, several more intimate sexual behaviours loaded on the same level, meaning that the sequence is interchangeable. These findings differ from results in the general population (de Graaf et al., 2009) and might be explained by the small sample size. However, also in this study, less intimate sexual behaviours preceded the more intimate ones. A linear trajectory in gaining sexual experience (de Graaf et al., 2009) (from less to more intimate behaviours) is common for the majority of boys in the general population as well. Gradually gaining experience offers the opportunity to develop skills and self-knowledge to interact with a partner and to refuse unwanted experiences. This study also revealed that a small group of boys with ASD seemed slower in starting to experiment with kissing and petting, the common first steps into partnered sexuality, compared with controls.

Different possible dynamics might explain why some boys with ASD did not, yet, have partnered sexual experience: individual characteristics (e.g., hesitance to approach potential partners, no interest in dating) and contextual aspects (e.g., few potential partners available) might impede the development of sexual relationships, and hamper gaining partnered sexual experience. Byers and colleagues (Byers et al., 2013) examined the sexual functioning of single adults with ASD. These researchers found a group of heterosexual adult men who had no partnered experience and who had higher levels of sexual anxiety, lower arousability, less dyadic desire, and less positive sexual cognitions. Possibly, two developmental trajectories can be discerned. The first group experiments with solo sexual behaviours, and starts experimenting with partners at an age comparable with typically developing boys. Their early dating experiences may contribute to the development of relationship skills and the self-confidence

to approach potential partners. A second, relatively small, group exists mostly of boys who have tried masturbation and experienced orgasm, but are slower to gain partnered experience because of internal and external barriers. Although most of these boys had watched internet porn, they did not use the internet for other sexuality-related means. The absence of partnered sexual experience does not have to be problematic: our results do not offer insight into how these boys felt about this. Last, a third developmental trajectory might exist. Two boys in this study reported no experience of an orgasm and also had no partnered experience. It might be possible that a small minority exists that does not, or to a lesser degree, experience sexual arousal. Feelings of asexuality in adults with ASD have also been previously reported (Barnett & Maticka-Tyndale, 2015; Bertilsdotter Rosqvist, 2014; Gilmour et al., 2012; Hellemans et al., 2007).

Partnered sexual experiences in boys with ASD

More than half of the boys with ASD had sexual experience with a partner. Exploration of the partnered experiences revealed that the boys' partners were mostly same-aged peers. More than half the boys in this study, with ASD and partnered experience, had at least two different sex partners and experimented with a variety of sexual activities. Boys in both the ASD and control groups had their first sexual experiences in different types of relationships. These results suggest that the sexual experience of the boys with ASD was mostly not occurring in a one-time only situation.

Several differences emerged between the experiences of the boys with ASD and the controls that warrant further attention, although they should be interpreted with care given the small sample size. Fewer boys with ASD seemed to be able to anticipate their first sexual intercourse. This might influence their safe sex practices and the decision-making process to consent with partnered sex: they have to decide on the spot, rather unprepared. About a third of the boys with ASD indicated that they did not use a condom when they first had sex, and half of them indicated some regrets about their first experience with sexual intercourse. Notwithstanding that their sexual debut came unanticipated for a number of boys, a third of the sexually experienced boys with ASD felt ready for sex earlier on. A small number of boys confirmed having coerced another to do sexual things, or had been forced by others. Although some of these boys reported risky, and possibly harmful, behaviours, most boys reported common and responsible experiences. The small sample and the low frequencies of these behaviours prohibit drawing firm conclusions on the prevalence of offending and victimisation. However, attention to offending and victimisation is needed in order to intervene and offer support as soon as possible. In addition, further research on the prevalence of offending and victimisation in adolescents with ASD is needed. The findings relating to partnered experiences stress the importance of comprehensive sexuality education with attention to social, communication, personal needs and desire, and safe-sex issues.

Strengths, limitations, and further research

This study is, to the best of our knowledge, the first to offer insight into the sexual functioning over time of a group of adolescent boys with ASD by comparing self-reported sexual behaviours with a matched control group. This study builds on the results of a first assessment of the sexual functioning in the participant group, and offers more insight into sexual development. The results of this study should, however, be interpreted in light of some limitations. First, selection bias might have occurred: the boys and their parents volunteered to participate in this study. People volunteering for sexuality-related research were found to have more sexual experiences and more positive attitudes [e.g., Strassberg & Lowe, 1995; Wiederman, 1999). Second, the data on lifetime sexual experience did not provide insight into the frequency and quality of sexual experience, the context, or a detailed description of the experiences. Differences pertaining to these issues might differentiate boys with ASD from their general population peers. Third, the range of intellectual functioning was broad across the participant group. Given the relation between intelligence, educational level and sexual development in this age group [e.g., Dekker et al., 2015; De Graaf et al., 2012], a smaller range would have strengthened our findings. Additionally, although the age range is limited, sexual experience can rapidly change in these years. In addition, depending on their age, the boys function in differing contexts (high school, college, university, work, in institutions or at home). Therefore, research in more homogenous samples should be considered. Last, the follow-up period between both assessments was relatively short. Differences might disappear or change later on in development. The group participating in this follow-up study was small in general and too small to study possible subgroups. The developmental trajectories described previously remain highly tentative and should be tested in further research.

Extensive follow-up of a large, homogenous group of boys with ASD would therefore be our primary suggestion for further research. A larger sample would allow for testing and exploring the different hypothesised developmental trajectories. Additional research on factors (e.g., anxiety, self-image) that are possibly related to or predict a specific developmental trajectory is needed. The present study revealed no clear relationship between the amount of ASD characteristics and partnered experience, so other aspects (e.g., anxiety, less desire) might be at stake. Additionally, further attention to partnered experiences (preparation, evaluation and interaction) is needed based on the exploratory findings in this study. Further attention to sexual diversity and its relation to well-being in individuals with ASD are needed. A mixed-methods approach, combining quantitative and qualitative methods, would probably offer valuable information to gain a better insight into sexual development in adolescents and adults with ASD. Because this study offers insight only into lifetime sexual experience, sexual functioning and well-being, and relationship

development of boys with and without early sexual experience later in life are subject to further research. Finally, sexuality development in girls with ASD needs attention in research.

Clinical implications

This study's findings support the frequently mentioned need for comprehensive and ASD-friendly sexuality education (Dekker, Vegt, et al., 2015; Hénault, 2005; Visser et al., 2015), beginning at an early age. Attention to the characteristics, and to the romantic and sexual experiences of individual boys, is necessary to tailor this education to the needs of each individual. First, the explorative and sexually active boys could benefit from discussing flirting, communication with a partner, sexual practices, and safe sex. Second, for boys without partnered experience, we could discuss the presence or absence of desire to find a partner, explore issues impeding them to find a partner, and their experience of approaching potential partners. Third, for boys without, or even with atypical, sexual interest, discussion of how they experience the absence of (typical) sexual interest, while observing sexuality and relationship development in their peers, could be helpful. Specific risks related to the different sexual developmental trajectories could also be assumed, without problematising sexuality in all boys with ASD: explorative boys might be at greater risk for getting into situations they are not yet prepared for, or getting into situations where they persuade their partners and cross boundaries; boys without partnered experience might feel different or frustrated. These specific risks might, however, also be present in typically developing boys. A more individualised approach is probably beneficial for boys with ASD. We believe that promoting sexuality-related education and communication by parents (Ballan, 2012; Holmes et al., 2015; Holmes & Himle, 2014; Nichols & Blakeley-Smith, 2009), professionals and caregivers (Holmes et al., 2014) could only add to the knowledge and skills to address partners and to have sexual experience in a pleasurable, consensual, and safe way.

CONCLUSIONS

Recent studies, including the present study, demonstrate that sexuality is part of typical adolescent development in most boys with ASD, as it is for their peers. A predominant problematising view on ASD and sexuality is again refuted, although several reasons for concern emerged (e.g., boys reporting regrets after their first time having sexual intercourse). The results of this follow-up study demonstrated mostly similarities in the sexual experience of boys with ASD and their peers in the general population. The finding that fewer boys with ASD than the controls had been kissing or petting a partner could be explained by a

group of boys that are, possibly, more anxious or hesitant to approach potential partners, and by boys who experience less interest in romantic relationships or sexuality. These hypothesised trajectories should be explored in further research. In the meantime, early and comprehensive sex education, and sexuality-related communication by parents and professionals surrounding boys with ASD, attuned to their sexual interest and experience, remains important to support them in dealing with and enjoying their sexuality and romantic relationships.

APPENDIX

Did you ever masturbate?
Masturbating: stimulating your penis with your hand. Some people call this jerking off

Have you ever French kissed (tongue kiss)?

Feeling and petting with clothes on, did you ever do that with someone?

Did someone ever jerk you off?
Jerking off: stimulating the penis with the hand

Jerking off or fingering, did you ever do that to someone?

Did you ever have sexual intercourse?
You have sexual intercourse if you go with your penis into the vagina of a girl. Some people call this 'having sex' or 'fucking'

Did someone ever give you a blowjob?
A blowjob: licking or taking the penis into the mouth

Did you ever have anal sex?
Anal sex: going with the penis in the anus

CHAPTER 5

Adolescent boys with an Autism Spectrum Disorder and their experience of sexuality: An interpretative phenomenological analysis

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ABSTRACT

This qualitative study explored how adolescent boys with autism spectrum disorder (ASD) experience their sexuality. Previous research has demonstrated that sexuality is a developmental task for boys with ASD, as it is for their peers. Case studies have suggested a relation between ASD and atypical sexual development; empirical studies on this subject, however, are scant and inconsistent. This study is based on interviews with eight boys, aged 16 to 20, with Asperger's disorder or autistic disorder. Interpretative phenomenological analysis of the data revealed three major themes relating to (a) how they experience sexual feelings, think about sexuality and think about themselves as sexual beings; (b) how they perceive messages relating to sexuality in their surroundings; and (c) how they experience finding and having a partner and partnered sex. We believe that attention to these themes is needed in assessment, education and further research.

Keywords: Adolescents, sexuality, autism, qualitative research, interpretative phenomenological analysis

INTRODUCTION

Sexuality is a complex phenomenon, expressed and experienced in feelings, thoughts, desires, fantasies, behaviours, identity, roles and relationships (WHO, 2006). Most research on sexuality in adolescence has focused on the prevalence of sexual experiences, the age of sexual debut and sexual trajectories (Fortenberry, 2013a). In-depth studies on sexuality development in adolescence are scarce (Diamond & Savin-Williams, 2009). Most studies on sexuality in individuals with ASD, as in the case of the general population, focus on the prevalence of sexual behaviours and on sexual knowledge (Dewinter et al., 2013; Kellaher, 2015). Studies based on self-report (Byers et al., 2013, 2012; Dewinter et al., 2015; Mehzabin & Stokes, 2011; Ousley & Mesibov, 1991) and parental or caregiver reports (Haracopos and Pedersen, n.d.; Hellemans et al., 2007, 2010; Holmes and Himle, 2014; Stokes and Kaur, 2005) have shown that sexuality is a part of life for individuals with ASD. Especially high-functioning adolescents and adults with ASD reported or demonstrated interest in relationships and partnered sexuality (Haracopos & Pedersen, n.d.). However, several studies (Bertilsdotter Rosqvist, 2014; Dewinter et al., 2013; Kellaher, 2015) suggested a high prevalence of feelings of asexuality, same-sex attraction, gender identity issues (De Vries et al., 2010; Jones et al., 2012), sexually inappropriate behaviours, deviant fantasies and offending ('t Hart-Kerkhoffs et al., 2009; Bleil Walters et al., 2013) in people with ASD.

Although adolescence is a critical period in sexuality development, studies on how sexuality is experienced by adolescents with ASD themselves are scarce. Complex sexuality-related issues, such as the development of sexual attraction, sexual identity and relationship experiences, are hardly studied in adolescents with ASD. Research on how adolescents experience their sexuality and relationships could offer insight into these issues, add to a better understanding of the possible impact of ASD on sexual development and offer cues for support (Barnett & Maticka-Tyndale, 2015; Byers et al., 2013; Byers & Nichols, 2014). The central aim of this study was to explore how high-functioning adolescent boys with ASD experience and give meaning to their sexuality and sexual development.

METHOD

Methodological approach

Interpretative phenomenological analysis (IPA) (Smith et al., 2009) is used as a framework for collecting and analysing data. IPA was developed to study people's lived experience and how they make sense of it. This approach has phenomenological (focus on lived experience),

hermeneutic (interpretation by the researcher as a way to gain insight into the experience of the participants) and ideographical (focus on in-depth analysis of particular participants) roots (Finlay, 2011; Smith, 2011b). In IPA 'the researcher tries to make sense of the participant trying to make sense of what is happening to him'. This process is also referred to as a 'double hermeneutic' (Smith, 2011a: p.10). IPA recommends in-depth analysis of data obtained from one or more individuals. If the study includes different participants, then the accounts are studied in-depth successively. Following this phase, the researcher looks for divergent and convergent patterns across cases. Earlier studies showed that IPA can be applied in research on people with ASD (Cridland, Jones, Caputi, & Magee, 2014; Humphrey & Lewis, 2008; Huws & Jones, 2015, 2008).

Participant characteristics

This study included participants who were male, aged 16 to 20, diagnosed with autistic disorder or Asperger's disorder (APA, 2000), with at least below average to higher range scores on a standardised intelligence measure (full scale IQ>70) and free of florid psychotic symptomatology. Boys who scored high on the Autism Diagnostic Observation Schedule (Lord et al., 2012), module 4, were included. Sexual experience was not a criterion for inclusion. We invited 18 boys to take part in this study; eight of them were willing to participate (see Table 1).

Table 1. Participant characteristics

Participant	Age	DSM-IV-TR[1]	Intelligence range	ADOS score	Living situation	Education/ work	Relational status
1. Andy	18	AS	Average	7 (ASD)	Independent	Unemployed	Relationship
2. Neville	19	AD - ADHD	Low average (PIQ>VIQ)	13 (Autism)	With parents	Employed	Relationship
3. Nathan	20	AD - ADD	Superior	14 (Autism)	With parents	Student	Single
4. Ben	16	AD – ADHD	Average	9 (ASD)	Group home / with parents	Student	Single
5. Nicolas	17	AD	Average	14 (Autism)	With parents	Student	Relationship
6. Tom	18	AD	Average	9 (ASD)	With Parents	Student	Single
7. Steven	18	AS	Superior	13 (Autism)	Independent with support	Student	Single
8. Zack	17	AD – ADHD	Average	5 (non-ASD)	Group home	Student	Single

Procedure

Eligible candidates had participated before in a longitudinal study on sexual development of adolescent boys with ASD. They agreed to be contacted for further research. The boys were approached after approval by the Medical Ethical Committee Brabant, Tilburg, the Netherlands (NL49082.028.14). The first author, who is a clinical psychologist, interviewed all participants. As he administered the ADOS to all the participants in the previous study, he was relatively familiar to them. The interviews took place at their homes (five), after classes in school (one), in the centre where the first author worked (one) and in the community institution where one of the participants resided. The interviews lasted 53 minutes on average (range 41.06 to 80.18 minutes). All interviews were semi-structured, starting with the question 'Can you explain what sexuality means to you?' The interviewer built on the answers of the participants by asking for details, examples, elaboration and clarification. The interviews were conducted in the boys' native language. Translations of the relevant quotes are included in this manuscript. The participants' names were replaced with pseudonyms. The following topics were discussed with each boy: falling in love, having a relationship, bodily changes, masturbation, partnered sexual experiences, sex education and pornography. Verbal expressiveness and the extent of sharing personal experiences differed between participants, resulting in variable richness of the data. All interviews were audiotaped and transcribed verbatim by the first author. The participants received a 5€ voucher after the interview.

Analysis

Every transcript was analysed as an individual case (Smith et al., 2009). In the first phase, descriptive (content), linguistic (language use) and conceptual (possible meanings) comments were noted next to each line in the transcript. Next, emergent themes were identified in these initial comments and the data. The themes were clustered on the basis of related content, as positions on the same dimension and by using abstraction. Finally, a descriptive report was written for each participant with the focus on how the participant experienced sexuality in his life. This was done, successively, for all interviews. Finally, all themes were integrated into one table, clustered and renamed, while staying close to the data.

Different strategies were used to support the credibility of the analysis. The researcher kept a diary during the data collection, transcription and analysis. This reflective document helped the researcher to be attentive to or 'bracket' ideas and feelings during analysis and be open to other meanings. The first author conducted, transcribed and analysed all interviews. The second and third author audited the analyses by reading the case reports, checking how these related to the themes and quotes, and challenging the meaning derived from the transcripts during analysis. In the light of these remarks, the first author went back to the manuscripts to look for support for alternative possible meanings and themes and clarified the wording of

the overarching themes. This discussion resulted in a better differentiation between individual (developing sexual self) and relational experiences, and on the grouping of subthemes within this developing sexual self (e.g. what I think is right vs. ideas about myself).

FINDINGS

The participants described a variety of solo and partnered sexual behaviours and relationship experiences. Five boys were or had been in a romantic relationship. The nature of these relationships varied from long-lasting (i.e. several months or more) and frequent face-to-face contacts, to mostly online contacts and short flirtations. All participants had experimented with masturbation, although not satisfactorily in the case of two of them. One boy never experienced sexual arousal, in contrast to another who was medically treated for hypersexuality. Five boys had partnered sexual experience; for four of them this included penile-vaginal penetration. One boy did not enjoy penetration and asked girls to undress before the webcam. A number of boys had sexual contacts outside a dating context, with friends or peers (three) and a professional sex-worker (one).

Three main themes emerged out of the analysis. The first theme, '*Developing sexual self*', referred to learning from the sexual responses of the body, personal ideas and norms relating to sexuality and defining oneself as a sexual being. Second, '*Interpreting sexuality-related information in my surroundings*' encompassed the interpretation of parents' and caregivers' messages and expectations and how peers dealt with sexuality. The boys also learned from sex education, the internet and internet porn. The third theme, '*Exploring relationships and partnered sex*', involved the interest in a relationship and learning about sex and relationships during interaction with partners. The themes are elaborated below and illustrated with quotes.

Developing a sexual self

All participants described sexuality as part of human functioning and had been exploring their sexuality. Bodily experiences seemed to be guiding this process (subtheme 1). The boys expressed a variety of beliefs about sexuality and relationships (subtheme 2) that related to their sexual behaviour. Furthermore, how they defined themselves as sexual beings (subtheme 3) related to the evaluation of their experiences and personal capabilities.

All boys described curiosity about sexual behaviours. Some boys spontaneously explored their own body and bodily reactions, whereas others only became curious after peers referred to sexual behaviour or experiences. The *body and bodily feeling of pleasure and attraction* appeared central in different accounts; these experiences offered cues to explore

and learn about sexuality. Andy (18) described his feelings for a boy at school and concluded that he was bisexual. Later on, he agreed with a boy to have sex. He described that he "had only once, (…) sexual contact with a… boy, however that was like… I thought that having sex with a boy was…not… not my thing… I had feelings like that for boys however the sexual part felt a bit strange". This experience led him to decide that he preferred sex with girls. Because of the arousal he felt after watching porn, Zack (17) was eager to experience sex. However, he described the actual experience as scaring and confusing. He explained that "sex was always on my mind, however… when I had sex myself, it was like 'ugh, no, I don't need that". Other boys reported pleasure and positive experiences.

Nathan (20) did not recognise sexual pleasure or attraction, although he recognised bodily changes (growing a beard) and physical sexual reactions (e.g. nocturnal emissions). He wondered about a 'brain helmet' to detect his sexual feelings in order to get to know them. He hardly felt any intrinsic motivation, other than cognitive interest, to gain sexual experiences. This is illustrated by the way he explained how he experimented with masturbation: "I thought it's just a part of it… but… no… I don't feel any need.". He also explained that feeling in love was unknown to him, for example by stating that:

> People sometimes ask (…) have you ever been in love, then I say no, I don't think so, because it is… falling in love isn't a thing of which you can say 'my toe nail gets blue, so I'm in love' (…) it's not measurable to me.

Just as Nathan seemed to feel little control over his absent or hidden sexual feelings, Zack (17) experienced little *agency* relating to his sexual interest and arousal. He discovered porn at the age of 10 and started to masturbate soon afterwards. At the time of the interview, he used medication to suppress his arousal. He described his sexual interest as obsessive: "I was constantly, constantly thinking about it, so every time I saw a girl, I thought 'wow'. That really was no good, because sometimes this happened in public places".

The boys held a variety of *ideas relating to sexuality* (e.g. which sexual experience one should have by when, what is appropriate) *and relationships* (e.g. the need for a relationship before one can have sex, the importance of consent). For instance, Nicolas (17) thought masturbation was a normal activity for boys of his age: "Yeah, for as far as I know, everybody does it". However, Ben (16) said: " It's dirty (his penis), it's… you don't do that… all those bacteria, it's a bacteria spot"

All participants described how they thought about themselves as sexual beings (sexual self): some felt confident, whereas others doubted their capacities and the kind of sexual experiences they had. For example, Neville (19) had several consecutive partners and expressed confidence in his ability to find a partner and to have sex: "It all went… I don't know… I'm rather

good at it". However, other boys evaluated their sexual experiences as different from what they perceived as normal. Nathan (20) seemed to feel different given the absence of recognisable sexual feelings: "People could regard it (absence of sexual and relationship interests) as a burden, however I see it as a benefit, it is cheaper". Zack (17) felt different, because he did not like penetration. His confusion became clear when he said "Why… why this, this isn't normal, I mean… how can you enjoy looking at it, while you don't enjoy doing it (…)".

Interpreting sexuality-related information in my surroundings

The participants referred to different sources of (in)direct information relating to sexuality and relationships. Boys derived ideas from the way their *parents and teachers talk and react* to issues pertaining to sexuality (subtheme 1), from remarks and jokes made by peers (subtheme 2) and from information they found on the internet (subtheme 3). Both watching porn and contact with peers seemed to stimulate sexual interest, whereas parents were perceived as communicating sexual norms and limits.

Several boys described and interpreted the hesitation of *parents and caregivers* to discuss sexuality. For example, Tom (17) reported that sexuality was hardly discussed in his family and he had concluded that his parents would be against it if he would date someone. A number of quotes revealed the taboo around the subject of sexuality. Ben (16) referred to '*confessing*' when he discussed his sexual experience with his parents; Andy (18) stated that it felt good that he did not '*have to hide*' anything during the interview, compared with the need to keep his sexuality hidden from parents and professionals. Only one participant, Neville (19), felt comfortable communicating about sexuality with his parents, which he related to his own lack of shame (again referring to a taboo). He found that his parents saw it as important that he knew about sex. Ben (16) explained that his parents did not initiate a discussion of sexuality or offer guidance, until he discussed his BDSM experience. "They never told me what to do or not, not that, only that one thing that I couldn't do (BDSM), but never told me what I could do, and so… they never told me what was allowed". Also Nicolas (17) seemed to experience his parents mainly as limit-setters, rather than as willing to discuss sexuality openly, recounting his mother's reaction when he asked her permission to let a girlfriend stay overnight: "She (mother) thought it was a bit too soon, I knew her (girlfriend)… for two days… if you think about it: it was too soon".

The way *peers* talk about sexuality was often mentioned as a stimulus to experiment with sexuality. Participants derived ideas about how to deal with sexuality from observing and talking with friends and schoolmates. For example, Nicolas (17) explained "Well, just like I heard friends talking about it (masturbation) and so, yes, tried it out myself and… ".

The participants referred to the *internet* as an easily accessible source of information and as a place where one could find pornographic materials. Nathan (20) for instance, described

the internet as "a source for information that, in this kind of situation, if you feel insecure, can be of help". The majority of boys (six) had been watching pornographic websites to get aroused. Although they all indicated that porn is not always realistic, it did offer them information on sexual behaviour. Andy stated that porn was like a fairy tale, which seemed to reflect that he understood that sex in porn is not always representative. However, after watching specific sexual behaviours on the internet, he wanted to "feel it for himself" and he stated that "You first look at the image you see, for instance in porn… it might be fantasy so you want to know how it is for real… so you look for information".

Most boys received sexuality education in school, as part of regular classes, and referred to the sex education classes as complete and good. Only one participant, Ben, described this as "childish" and stated that he had wanted more information.

Experimenting with relationships and partnered sex

Subthemes in this section included looking for a partner (subtheme 1), exploring relationships and partnered sex (subtheme 2) and adapting to a partner (subtheme 3). All but one of the boys felt *interest in a relationship and partnered sex*. Nathan (20) ascribed his absence of interest in a romantic relationship to his unawareness of sexual attraction and arousal. He also negatively anticipated the idea that another person would intrude on his personal space. When the interviewer asked about his interest in having a romantic relationship, he responded: "I don't want to think about it, honestly… I understand that others like it though, like you hear people say".

Apart from being interesting, it seemed challenging for several boys *to find and approach a partner*. Steven (17) described internal and external conditions hampering his opportunity to find a partner. On the one hand, he found it hard to get to know a girl well enough as he said that "If I have contact with someone and there is a basis of trust, then…, however I never trusted anyone enough that it could happen". On the other hand, he experienced situational obstacles in finding a partner: he argued that his chances of meeting a girl were reduced because he mostly met boys with ASD, or, in a rare case, a girl with ASD.

> I don't meet anyone because one in ten autists is, in my experience, female, so statistically seen and demographically, there is a strong lack in my surroundings in the percentage of women and then it also becomes difficult to find a relationship.

Tom (17) described the influence of ASD-related communicative and social impairments on his ability to develop a relationship and felt inhibited about approaching girls: "It is difficult for me to get information out of conversations, so to say, to filter the main from the side-issues is very hard to me, so… yeah, that could be problematic in a relationship".

Although the boys were aware of the possible risks of online dating, several participants described the internet as a medium to meet and have contact with potential partners.

Five of the boys had been in a *relationship and had experimented with partnered sex*. This sexual experimentation was situated both within romantic relationships and outside a dating context. For example, Nicolas (17) told he once had sex with a female friend when she stayed overnight to watch a movie.

> Actually (it happened) a bit strange…a close female friend came over to stay overnight and… we made it cosy in my room, watched a movie and so on and then… we just started kissing and then… and one thing turned into another.

Most boys evaluated their partnered sexual experiences as positive and pleasurable, and tried to fit in with the wishes and limits of their partners. Andy (18) experimented with different kinds of sex partners. He felt that having a relationship added value to sex, stating that a relationship "makes the puzzle round". As he mixed expressions, so he also struggled with the understanding of relationships. He described the emotional distance he experienced in different short sexual relationships and how he valued feeling close to his partner. He explicitly described the negotiation of his sexual desires with his new partner and felt more confident that he would not coerce her unintentionally. Andy found his partner willing to experiment sexually so that he could find out what he liked. However, he remained concerned that she did not dare resist his proposals: "You could say it's OK and afterwards you think that is not like that… (…) I really have to see that she actually agrees, because she says so but…". Several other boys stressed the importance of consent by their partners and emphasised that they did not apply pressure to their sex-partners. This emphasis on consent in sexual interaction possibly reflected the concern of parents and educators that these boys might coerce partners. One boy was convicted for sexual offending and described the use of coercion to get others to fulfil his sexual needs. His main concern was that these girls would not want to have contact with him later on, reflecting limited insight into the perspective of his victims.

Finally, having a relationship posed demands on some of the boys, as illustrated by Andy (18) saying "Spending the weekend together is enough (laughs) just because (…) she has a totally different pace and you feel that it doesn't work out well". All boys who had been in a romantic relationship referred to the effort *needed to adapt* to the pace, habits and demands of a partner. This adaptation was challenging for different boys. Zack (17) described how he dared not to refuse to have penile-vaginal intercourse: "I really did not like it (penetration), it was because I did not want it myself, but I could not say it, so...".

These quotes illustrate the effort it demands from some participants to change their own

habits and routines, share personal domains or indicate personal limits, apart from the desire to have a partner or to have partnered sex.

DISCUSSION

All boys in this study had thought about and experimented with sexuality and relationships, albeit in different ways. Earlier studies mainly focused on sexual behaviour, knowledge or education (e.g. Dewinter et al., 2015; Hellemans et al., 2010; Stokes et al., 2007) and were hardly based on self-report (Dewinter et al., 2015). This study, based on first hand information, illustrates the complex interaction between information processing, education, social learning and interaction, and identity development in relation to sexuality and romantic relationship development.

Our findings do not support a predominant problematising view on sexuality in adolescents with ASD (Byers et al., 2012; Kellaher, 2015). However, next to common and age-appropriate sexual experiences, several challenges for these boys with ASD, which related to sexuality and relationships, came to light in the interviews. Sensory and information processing issues related to ASD, such as recognising one's own bodily signs and feelings (e.g. feeling arousal and attraction) or obsessive interests, and social and communication difficulties, such as understanding explicit and implicit messages from parents and peers, influenced how participants experienced and thought about sexuality, and how they interacted with (potential) partners. The boys also learned from observing peers and surfing on the internet. The perception of their sexual and relational experience, their social and communicative skills and their ideas about how things should be, seemed related to the way in which they defined themselves as (in)competent, strange or even dangerous sexual beings. Although some boys were self-confident, others felt ashamed or different because of their sexual functioning, described negative experiences or experienced rejection by others and even legal consequences. These findings support the importance of healthy sexual development in general well-being and identity development (Tolman and McClelland, 2011; WHO, 2006).

Although the participating boys lived in countries with liberal sexual attitudes (De Looze et al., 2014) and were allowed to participate in research on sexuality, the taboo around sexuality was recognisable in their reactions and expressions. Most boys in this study were not used to discussing their experience of developing as a sexual being. Reluctance to discuss sexuality by adolescents with ASD, their parents (Holmes and Himle, 2014; Nichols and Blakeley-Smith, 2009) and professionals (Holmes et al., 2014) might reinforce each other and hamper personal discussion of this topic. Yet discussing the boys' experiences with and

ideas about sexuality and relationships, as done in this study, is an important way to gain insight into the challenges that some of them are facing.

The importance of different sources for sexuality related information, already studied by Stokes and colleagues (2007), is illustrated by our findings. Apart from explicit education about sexuality by parents and teachers, the boys interpreted implicit information (e.g. what is not said, non-verbal reactions) on sexuality and relationships provided by parents and teachers. In contrast to other studies (Brown-Lavoie et al., 2014; Stokes et al., 2007), peers were often mentioned as a source of information and as a trigger to explore sexuality and relationships. Last, the internet is an important, although not always reliable, source for sexuality-related information.

Strengths, limitations, considerations and directions for future research

This study offered insight into how sexuality is experienced by adolescent boys with ASD. Discussion continues about the need to adapt hermeneutic phenomenological methodology for data collection and analysis in people with ASD (e.g. by using visual support in interviews) (Chown, 2011; Cridland et al., 2014; Newman, Cashin, & Waters, 2010). In this study, the richness of the data was influenced by the limited expressive language of two participants and by the extensive use of formal language of another participant. Five boys gave extensive reports, using complex and expressive wordings. ASD features were recognisable in these accounts (e.g. a stereotypical interest in numbers, literal interpretations and expressions). We consider knowledge about ASD features and information processing crucial for the understanding and interpretation of the data.

The results should be replicated and be supported by further quantitative and qualitative research. Further research into the role of bodily perception of arousal, the kind of relationships that offer a context for partnered sexuality and how sexual experiences in those contexts are evaluated also seems warranted.

Clinical implications: discussing experience

This study confirms that sexuality and building relationships are part of adolescent development in boys with ASD that can offer pleasure and add to self-confidence, as well as distress. Uncertainty or negative experiences and feelings regarding sexuality can impede general well-being. Researchers in the field of sexual development and functioning in adolescents and adults with ASD have already stressed the need for early and comprehensive sex education (CSE) including attention to relational and social skills (e.g. Attwood et al., 2014; Byers and Nichols, 2014; Dewinter et al., 2015; Stokes, 2007; Stokes and Kaur, 2005). Parents and professionals can, actively and repeatedly, invite adolescents to discuss personal feelings and ideas about sexuality and relationship-related issues as a way to identify and understand

possible challenges in the adolescents' experiences and offer them attuned support. Sensory perception, self-perception, ideas about sexuality, interpretation of (expectations from) others and of online information, expectations relating to relationships and interaction with potential partners are important issues in sexuality education of adolescents and should get attention in discussing sexuality throughout life with individuals with ASD. Although recent studies refute a problematizing view on sexuality and ASD, attention to possible harmful sexual and relational behaviours and experiences is warranted, in order to intervene timely and offer support. This study also suggests that these boys have experiences outside the traditional heteronormative discourse (e.g. same sex contacts, sexual contacts outside of a romantic relationship), which we should be prepared to discuss openly.

CONCLUSION

All boys in this study experienced sexuality as a part of their development, even if they did not experience sexual arousal, or had no partnered sexual experience. Spontaneously discussing personal sexuality and relationship experiences seemed challenging for several boys and their surroundings, although this probably offers an important way to get support when needed. Parents, caregivers and professionals should initiate discussion on the way in which adolescents with ASD experience their sexuality and relationships, and support sexuality development and well-being.

SUMMARY AND GENERAL DISCUSSION

INTRODUCTION

The overall aim of this thesis was to explore sexuality development in high functioning adolescent boys with Autism Spectrum Disorder (ASD). A mixed (quantitative and qualitative) methods approach (Creswell & Plano Clark, 2011) was applied in the hopes of a better understanding of sexuality in the group under study. This concluding chapter offers an overview of the main findings in this thesis, a discussion of the results, directions for future research, and implications for parenting, education, and clinical practice.

Summary of key findings

Chapter 1 offered a review of the existing research on sexuality and ASD from 1980 to 2012. In general, research on sexuality in children, adolescents, and adults with ASD is scant: 55 publications were selected, including 29 case studies. Although these results are valuable, they deal with several substantial methodological issues, such as small sample sizes, heterogeneous participant groups, and the absence of a control group. Although sexuality is often seen as a private matter, only few studies were based on self-report of adolescents and adults; the majority used parents and caregivers as informants.

Most studies focused on actual and observable sexual behaviours. Solo sexual behaviours seemed common, while only few adolescents and adults with ASD had partnered experience. Better social functioning was related to more relationships and partnered sexual experience, and with fewer inappropriate behaviours. Several studies and case reports suggested a higher prevalence of atypical and sometimes inappropriate behaviours (e.g. fetishisms, public masturbation, offending). A relation between sexual victimisation and inappropriate sexual functioning at older age was found. However, the existing studies did not offer insight into the prevalence of atypical sexual development in adolescents and adults with ASD.

Only a few studies looked into the development of sexual selfhood or individuality: the way adolescents think about themselves as sexual beings, how they feel about sexuality and pleasure, their (gender) identity and being in a relationship with another (Fortenberry, 2013b; Tolman & McClelland, 2011). While adolescents and adults with ASD in most studies had sufficient basic sexual knowledge, this appeared not to be a guarantee for adequate sexual and social behaviours. A higher prevalence of same-sex sexual attraction, gender identity disorders and dysphoria was suggested, although this was not supported by systematic research. Lower sexual well-being, and satisfaction appeared in groups with ASD, related to lower degrees of social and communicational functioning, and to relationship experience. Studies on sexual socialisation, referring to the contexts and ways in which adolescents gain sexual knowledge, norms, and experiences (Tolman & McClelland, 2011),

mainly focused on how parents and caregivers felt about offering sexuality education to their children with ASD. Parents mainly tended to discuss sexuality if they thought this topic would be relevant for their children. However, they doubted when and how to do this. Some parents felt concerned about the way their children would deal with sexuality and about how others would interpret the behaviour of their children with ASD. Parents demanded support to discuss sexuality with their children with ASD in different studies. Studies on the effect of sex-education programmes are lacking. Because of the social difficulties relating to ASD, peers seemed to have a less prominent role in sexual socialisation compared to adolescents in the general population. Although research on sexuality is scant, especially on factors and mechanisms underlying sexual development, the existing results indicated that a substantial number of adults and adolescents with ASD show sexual behaviours. Romantic relationships and partnered sexuality were described in people with high-functioning ASD, with higher levels of social and communicative skills. The importance of sexuality education was stressed, however it seems challenging to parents and professions.

In *Chapter 2*, the aim was to compare the prevalence of sexual behaviours, sexual interests, and attitudes in adolescent boys (n=50) with high-functioning (FSIQ>70) ASD and in controls (n=90). A similar number of boys in both groups had experience with common solo (masturbation, orgasm) and partnered (kissing, hugging, manual and oral sex, sexual intercourse, anal sex) sexual experiences. Sexual attitudes, and sexual attraction did not differ between both groups. The only difference was that boys with ASD seemed more tolerant towards homosexuality. The number of boys in both groups who reported sexual coercion or victimisation was very small. The results of this study offered little insight into the quality and context of the sexual experiences. Based on these results, sexuality is considered a normative part of adolescent development in boys with ASD, as it is for boys in the general population. Early and comprehensive sexuality education for adolescents with ASD is promoted.

Chapter 3 described the comparison of parental and self-report (n=43 parent-adolescent dyads of the original 50 participants) on the lifetime sexual experience of adolescent boys with ASD. The results of this study confirmed the assumption that parents underestimated the sexual experience of the adolescents with ASD. This may not be different from parental underestimation of sexual experience in adolescents in the general population. About half of the parents in the present study did not know whether their son had experience with masturbation. Relatively more parents were aware of the partnered experiences. These remain preliminary results given the small and specific sample and the absence of a control group, so they need further corroboration. However, underestimation of sexual experience by parents might result in limited sexuality related communication and education with their sons, possibly hampering healthy sexual development in these boys. This study's results also put earlier research based on parent and caregiver report into perspective.

Chapter 4 reported on the follow-up of lifetime sexual experience of the boys with ASD (n=30 of the original 50 participants) in 2014 (age 16-20). The sexual experience of the boys with ASD was compared to a matched general population group of boys (n=60). Again, major resemblances between boys with ASD and controls relating to sexual experience appeared. Only, a few more boys with ASD had no partnered sexual experience. Fewer boys with ASD than controls reported lifetime experience with kissing and petting. These partnered behaviours preceded other, more intimate, partnered sexual behaviours in typical sexual development. This finding suggests that a subgroup of boys did not progress in their sexual development in comparison to peers in the general population. The majority of the boys with ASD without partnered experience reported solo experiences (masturbation, orgasm) and had visited pornographic websites on the internet. Only two boys had not yet experienced an orgasm. We hypothesised that three different developmental trajectories might exist: 1) a group that has experience with solo sex, who find a partner and actively explore partnered sexuality at a comparable age as peers in the general population, 2) a group with solo sexual experience but without partnered experience, related to being more hesitant, experiencing barriers to meet potential partners, or having less interest in dating, and 3) a group that experiences less interest in sexuality and relationships in adolescence. These trajectories could explain limited partnered experience in some adults with ASD (Byers et al., 2013). The present study confirmed that sexuality is a part of normal adolescent development in the majority of boys with ASD, as it is for their peers, however different developmental trajectories might exist. Early comprehensive sexuality related education and communication by parents and professionals is important for all boys with ASD, however an individualised approach is advisable. We suggested that sexuality education and communication should be attuned to the sexual development of each individual boy.

The aim in *Chapter 5* was to gain more in-depth insights into how boys with ASD experience their sexuality. An Interpretative Phenomenological Analysis (Smith, Flowers, & Larkin, 2009) using accounts from eight boys on their experience of sexuality revealed three major themes: 1) becoming a sexual being, i.e. the way the boys felt sexual arousal and attraction, their beliefs and internalised norms, and the way they evaluated their sexual experiences and feelings compared to these norms, 2) interpreting sexuality related information in their surroundings, and 3) experimenting with partnered relationships and sex. The boys described a variety of typical and sometimes atypical sexual experiences. The taboo on discussing sexual experience clearly appeared in the accounts. This study offered deeper insight into the complexity of this developmental domain and indicated the need for broadening research on sexuality and ASD (e.g. to issues relating to sexual selfhood). Listening to the experience and sense making of people with ASD is probably the most valuable source of information to tailor sexuality related education and communication.

OVERALL DISCUSSION

Does sex matter for boys with ASD?

The statement that 'sex is not for the majority of autistic people' (Torisky & Torisky, 1985) is countered by this thesis' results, specifically for high-functioning adolescents boys. Based on the findings of the quantitative and the qualitative study, boys with ASD deal with sexuality and romantic relationships in different ways. The majority of the boys, about 70%, had solo- and partnered sexual experiences at a comparable age as their general population peers by the end of their teen years. They started experimenting with masturbation in their early teens, at comparable age as their peers in the general population, These boys with ASD had their first partnered sex in a variety of types of relationships, as did their peers in the general population. In their late teens, a second group of about 25% of the boys with ASD only reported solo experiences compared to less than 10% of the boys in the general population. This finding suggests that a larger group of boys with ASD does not, or only when older, gain partnered sexual experience. Boys in this thesis mentioned internal (e.g. anxiety, lack of skills) and external (e.g. special education schools) barriers to find a partner and develop a relationship. As in the general population, some boys in this group might just not feel up to having a (sex) partner while others feel hampered to experience partnered sex. A, minor, third group (about 5%) reported no solo or partnered sexual experience and had little interest in sexuality.

Similar sexual experience in adults with ASD living in the community compared to peers in the general population was demonstrated earlier by Gilmour and colleagues (2012), while others demonstrated less sexual experience in adolescents and adults with ASD (Hellemans et al., 2007; Ousley & Mesibov, 1991). Differences pertaining to sample characteristics such as mixed sex groups, broad intelligence level range, different functioning levels (e.g. boys living in institutions (e.g. Hellemans et al. 2007) vs. in the community (e.g. Gilmour et al., 2012)), and to research methods (self- vs. caregiver-reports, different measures) make it hard to compare these results. Some explanations for these differences can be assumed. First, this thesis did demonstrate that a substantial number of parents underestimate or are unaware of the sexual experience of their adolescent sons. These findings might also count for other third party reports (for example caregivers in institutions) and explain the lower numbers in the aforementioned studies. Second, a substantial number of the participants in this thesis lived in the community and all were high functioning, in contrast to samples in other studies (e.g. Hellemans et al., 2007), possibly explaining their lower level of sexual experience. Generalisation should thus be done with care. Yet, the results of this thesis indicate that sexuality matters to boys with ASD and can be helpful to parents and educators to understand and be aware of sexuality development in adolescents with ASD.

What then is normal sexual development in boys with ASD?

The majority of boys with ASD in this thesis had masturbated, starting around age 13. At age 15, a third of them had some partnered experience and by then one in four boys had had sexual intercourse. By the end of their teen years, about half of the boys had sex with a partner. So, these are common behaviours in high-functioning adolescent boys with ASD. This supports the statement that sexuality is a normative part of adolescent development (Tolman & McClelland, 2011): adolescent boys with ASD can be expected to have solo and partnered sexual experiences.

Normativity does not imply that every adolescent boy, with or without ASD, should masturbate or have sexual intercourse: some, although a minority, do not. Also, the idea of having a relationship was not attractive to all boys: for instance, adapting and sharing your personal domain seemed complicated to some boys. Based on the definition of sexual health (WHO, 2006), ideally all boys would feel fine about the way they experience their sexuality, whether or not they have sexual feelings and desires. The boys that desire partnered sex should have ways to accomplish this and experience them in a pleasurable, safe, and socially acceptable, however not necessarily in a traditional hetero-normative way (i.e. in a long-lasting heterosexual relationship). Boys without sexual interest should know that this is also fine and understand how others feel about sexuality and relationships. This thesis demonstrated that not all boys accomplished this: some felt inhibited to find a partner, or different from the expectations of their surrounding, and one boy experienced his desires and sexual urges as uncontrollable.

The definition of sexual health offers a framework to evaluate, with these boys and their parents, how they function on the sexual domain and what they need in their sexual development (for example, social skills and support to find a partner, vs. normalisation of the absence of sexual feelings).

Is a problematising view on sexuality in adolescent boys with ASD warranted?

This thesis mainly refuted problematising views on sexuality and ASD. The majority reported typical sexual beliefs, attitudes, and experiences. Both boys with ASD and their peers in the general population had positive and permissive attitudes towards sexuality. The boys with ASD even showed higher acceptance towards homosexuality. Only a few boys in both groups reported sexual coercion or victimisation. However, some of the boys with ASD in this thesis described atypical and, sometimes, inappropriate sexual behaviours. The accounts of the boys in the qualitative study confirmed that lifetime sexual experiences could refer to a range of sexual experiences: common and age-appropriate, sometimes atypical (e.g. BDSM), and, exceptionally, inappropriate (e.g. coercion). Most boys experienced little guidance in the way they deal with sexuality. It seemed an individual challenge to understand their body

and feelings, to understand societal norms and expectations, to find and attune to a partner. Information on partnered sexual experiences revealed that attention is needed for issues such as preparation for and evaluation of their sexual debut (penile-vaginal penetration), and condom use.

The results in this thesis warrant a nuanced view: sexuality is part of adolescent development, also in ASD boys. Although the majority had typical and positive experiences and beliefs, some boys had negative experiences or showed risky and atypical behaviours and ideas. To what extent this group is larger than the normal population cannot be concluded from our studies. This thesis only offered limited insight into specific sexual interests and behaviours that were related to ASD in earlier publications, such as stereotyped interests or sexual preoccupations. Notwithstanding, early and comprehensive sexuality education, and open communication with boys with ASD is probably the most obvious way to support sexuality development and to detect possible problems.

About birds, bees, and pornography: learning about sexuality and relationships.

Information pertaining to sexuality and relationships can be found everywhere: in what parents tell or do not tell, in observing peers, on the internet, in sexuality education at school, in media and porn, in the interaction with other caregivers, caregivers and partners. The boys in this thesis described subtle, often contradictory, messages and expectations they derive from interpreting others (e.g. parents, educators, peers, actors in porn). Personal communication about their experiences and beliefs was new to several participants in this thesis.

Parents appeared in this thesis more frequently as limit and norm setters, rather than explaining and stimulating their children on how to enjoy sexuality in a healthy way. However, several boys found it awkward to discuss sexuality with their parents, even when these adults seemed very open about the subject. Hesitations on both sides might make sexuality related communication a challenge. Holmes and Himle (2014) found that parents of high-functioning boys with ASD do discuss issues pertaining to privacy, abuse prevention, hygiene, and basic aspects of relationships. However, few parents communicated about sexual health and more complex aspects relating to sexuality. Parents in the present study tended to underestimate the sexual activity of their children, especially masturbation. This underestimation might be one of the factors explaining that a substantial number of parents do not discuss masturbation and other sexual behaviours with their children (Holmes & Himle, 2014). Also few parents in the general population discuss masturbation with their adolescent children (Diiorio et al., 2003; Frankel, 2002), However, masturbation has an important role in sexual development, as a way to learn about sexual pleasure (Fortenberry, 2013b). The discussion of masturbation might be specifically relevant for boys with ASD:

some boys do not spontaneously develop adequate masturbation techniques, experience frustration and have questions, or hurt themselves (Haracopos & Pedersen, n.d.; Hellemans et al., 2007).

The interviewed boys talked about peers and schoolmates as an important source of sexuality related information, by telling jokes, bragging and asking questions (e.g. have you tried masturbation?), which is in contrast to findings by Stokes, Newton, and Kaur (2007). However, this difference might also be an effect of the use of self-report in this study compared to parent report by Stokes and colleagues.

Over the last decade, almost all adolescents in the western world gained access to the internet, on different kinds of devices (e.g. computer, tablet, smart phones) (e.g. Livingstone, Haddon, Görzig, & Olafson, 2012). The internet has thus gained importance as a source for easy access to sexuality related information and materials. Research in the general population revealed positive influences of internet access on sexuality as well as risks (e.g. Owens, Behun, Manning, & Reid, 2012; Smith, 2012). Research on this issue in adolescents and adults with ASD is still limited. The boys in this thesis who were interested in sexuality almost all watched sexually explicit material on the internet. Although most of them were convinced that they knew how to interpret porn (for example as unrealistic), it also was informative and created expectations in some. This thesis also illustrated that boys use the internet to look for information and explanations. A substantial number of the boys with partnered experience also used the internet to contact others for sexuality and dating issues. Attention in sexuality education to the interpretation and use of sexuality related information and materials on the web is thus important.

Finally, the participants learned about sexuality in the interaction with their partner: where their own desires met those of their partners, influencing the sexual experience of the boys. We found examples of how boys experimented, and sometimes struggled, in the interaction with their partners. It is presumable that some boys with ASD, with social impairments, have limited interactional competence (Vanwesenbeeck, Van Zessen, Ingham, Jaramazovic, & Stevens, 1999), i.e. the capability to define and achieve personal goals and desires, and at the same time maintain a positive relationship with and attune with a partner. Some issues found in this thesis (unexpected sexual debut, regrets after first time sex, specific sexual experiences) might be explained by these impaired interactional skills. This might make some boys with ASD prone to acquire unwanted or atypical experiences: in some boys on their initiative, in others on their partner's.

Taken together, learning about sexuality appeared as a complex process for the participants in this thesis and encompassed more than learning from sexuality education. However, sexuality education could probably be of help to be prepared and know where to find support, to deal with this complexity.

Once upon a time in the West of Europe

The results of this thesis should probably be interpreted in light of its historical and geographical context. In general, people in the Netherlands and Belgium hold rather liberal attitudes towards adolescent sexuality, compared to other countries (de Looze et al., 2014). Comprehensive sexuality education (CSE) is part of most schools' curriculum in both these countries, in contrast to, for instance, the abstinence only sexuality education common in some parts of the USA (Kendall, 2014). Probably, most boys in this thesis learned about sexuality and relationships at school. Over the last two decennia, attention to positive aspects of adolescent sexuality is also more common, compared to a narrow focus on risk prevention before (O'Sullivan & Thompson, 2014; Tolman & McClelland, 2011). So, boys with ASD in this thesis might have received more liberal and comprehensive information pertaining to sexuality and relationships, compared to boys in other cultures and in earlier studies.

Finding out about your sexuality

Boys in this thesis with and without sexual experience and interest reflected about themselves in relation to sexuality (for example 'I'm good at it' vs. 'I feel different'). Their self-definition was related to how they thought about their personal competences and limitations (e.g. 'I easily misunderstand others' vs. 'I'm good at flirting'), how they experienced their bodily feelings (e.g. 'I feel attraction to girls' vs. 'I do not know what I like'), and how they evaluated their solo and partnered experiences (e.g. 'It felt good' vs. 'It was wrong'), compared to the norms they deduced from their surroundings (parents, peers, educators, and internet). Possibly, these self-definitions influence further sexual development: a confident boy will approach a partner more easily, compared to a more hesitating peer. These processes are already described in adolescents in the general population (Fortenberry, 2013b), however they have received limited attention in people with ASD. In a recent study in adults with high-functioning ASD (Byers et al., 2013), feelings of sexual anxiety, fewer positive thoughts related to sexuality, lower arousability, and less desire were related to the absence of partnered experience in a group of men. The direction of the relationship between ideas about oneself in relation to sex and relationships on the one hand, and partnered sexuality is unknown. Most boys in this thesis experienced the sexual function of their body as a part of human functioning and integrated it adequately in their lives. However, individual accounts showed that sexual arousal could also feel 'strange'. One boy described how he never felt something that he recognised as sexual arousal, while another boy described how he felt obsessed, and hardly experienced agency over his sexual desire. Since sexual health is 'a state of (…) well-being in relation to sexuality' (WHO, 2006), attention should be paid to how adolescents and adults think about themselves in relation to sexuality and how they can

feel fine about it. This is probably far more complex and personal to discuss, compared to offering information about bodily development and safe-sex practices.

STRENGTHS AND LIMITATIONS

The strengths of this thesis lie in the selection and assessment of a sample of adolescent boys diagnosed with ASD and the careful matching of their reports to control groups. This study was also, to our knowledge, the first to compare self- and parent report on sexual behaviours in adolescents with ASD. The use of self-report and interviews gave boys with ASD a voice in research on their development and offered insight into their sexual development. The adaptation of a mixed methods design gave different kinds of insight (prevalence of behaviours on group level vs. personal experience and sense making) in the phenomenon under study. Notwithstanding these strengths, the results in this thesis should be interpreted in the light of the following limitations.

Sample

For different reasons, the results of this participant group can only be generalised with caution. First, the participants in this thesis are a specific subgroup within the ASD-population (only high-functioning males), limiting the generalisability of the results to other groups (e.g. girls, boys with lower intelligence levels). Second, selection bias is likely when sexuality research is conducted with volunteering participants (Bogaert, 1996; Strassberg & Lowe, 1995; Wiederman, 1999). Only a third of all boys and parents who received information about this study agreed to participate. The non-participants may have differed from the participants pertaining to their sexual development and functioning. Also, their parents might have less liberal opinions pertaining to sexuality, be more protective or assume that their children had no sexual interest. However, research in the general population demonstrated the limited influence of selection bias in sexuality research (Dunne et al., 1997). Third, attrition bias might also be at stake in the follow-up study: twenty participants could not be approached or did not volunteer to participate in the follow-up study. However, no relevant differences existed between participants and non-participants relating to ASD-characteristics, sexual experience, age, and educational level. Last, the sample size was not large enough to study possible subgroups relating to, among others, ASD characteristics and sexual experience.

Measures

The questionnaire used in the quantitative studies questioned common sexual behaviours, knowledge and attitudes in the general population. Atypical behaviours, described in various

case-studies (Dewinter et al., 2013; Kellaher, 2015), were not included in the survey. So, this thesis does not offer insight into the nature and prevalence of specific atypical interests and behaviours in adolescents with ASD. In general, there is a dearth of knowledge on atypical sexual behaviours (e.g. hypersexuality) and interests (e.g. fetishism) in adolescents. This fact might be related to the hesitance of researchers and Ethic Committees to include adolescents in sexuality related research (Kuyper, de Wit, Adam, & Woertman, 2012).

The present thesis only offered insight into lifetime sexual experience. No information was available pertaining to other aspects that might differentiate boys with ASD from their peers in the general population: e.g. data on the frequency of different sexual experiences over a specific time-period, the context (e.g. partner characteristics, timing) of sexual experiences. Therefore, this thesis' results only highlighted specific aspects of sexual functioning, while others remain understudied.

Follow-up

The follow-up time remained limited. The participants completed the sexuality questionnaire at only two times, with on average 2 years in between. Studies in the general population (e.g. de Graaf et al., 2012; Fortenberry, 2013) showed that boys and emerging adults gain sexual experience after the age of 20. In order to corroborate the assumption that a substantial group of boys with ASD only has partnered experience later on in life, further follow-up is necessary.

IDEAS FOR FUTURE RESEARCH

Based on the findings in this thesis, several suggestions for further research, apart from the necessary replication of these findings, can be made.

First, attention is needed on the further sexual and relational development of boys with ASD later on in their development. The question remains how the boys with and without sexual interest and experience in adolescence handle relationships and sexuality later on in their lives. For example, some boys with partnered sexual experience might only have had a one-off sexual experience while others develop long-lasting relationships. It is unknown whether these boys are or feel able to maintain a romantic relationship, or how these early sexual experiences influence later interaction competence. Also, boys without partnered experience in their teens might find a partner, build a long-lasting relationship, and enjoy their sexuality. These examples illustrate that it remains unknown how early sexual and relationship experiences influence sexual well-being and health later on in life. Follow-up of a large enough group of children, adolescents, and adults with ASD, over longer periods

of time could add to our understanding of sexual development in adolescents and adults with ASD. Apart from questions on lifetime experience, questions on sexual behaviour in a short period before completing the questionnaire (e.g. in last month, how many times did you….) could reveal additional information on their daily sexual functioning. In addition, qualitative research in emerging adults with ASD might offer insight into sexuality and relationship development in boys with ASD. These studies could make it possible to explore developmental trajectories, which, in turn, could lead to cues for attuned sexuality education, communication, and support.

Second, research on sexuality development in other groups of adolescents and adults with ASD is necessary. Especially research in girls and women with ASD is scant.

Third, attention to gender, and sexual attraction within people with ASD might help to verify and understand the (clinical) impression (Byers et al., 2013; de Vries, Noens, Cohen-Kettenis, van Berckelaer-Onnes, & Doreleijers, 2010; Gilmour et al., 2012; Hellemans et al., 2007) that a substantial number of adolescents with ASD identifies as belonging to a sexual minority or deal with gender dysphoria. Further quantitative and qualitative research in individuals with non-heteronormative (e.g. same-sex attraction) and atypical interests (e.g. fetishism) could help to understand the nature of these interests, their integration in sexual identity, and relation to sexual health.

Fourth, investigation of developmental histories of adolescents and adults with ASD who demonstrated inappropriate sexual behaviours or have sexually offended, and systematic evaluations of interventions in this group are important to gain understanding of the development and treatment of inappropriate sexual behaviours. The effects of societal reactions (e.g. conviction, detention) and interventions (e.g. relapse prevention, pharmacological interventions) on sexual development and sexual health in adolescents with ASD should be subject to further research.

Finally, in general, theoretical and methodological advances in general sexuality research should be integrated in research on sexuality in adolescents and adults with ASD. For example, based on the findings of the IPA-study, embodiment theories (Finlay, 2011; Tolman, Bowman, & Fahs, 2014) seemed promising in further research on sexuality in adolescents and adults.

CLINICAL IMPLICATIONS

Strengthening awareness about sexuality in adolescents with ASD

Parents, caregivers, professionals, and the adolescents with ASD themselves should be aware that sexuality is a normative part of adolescent development. This can be realised by

making information pertaining to sexual development in adolescents with ASD accessible, among others in publications, leaflets, and on informative websites. Professionals can have an important role in creating awareness about sexual development and in the support of parents to discuss sexuality issues with children and adolescents with ASD. They should thus be skilled to teach about and discuss sexuality and romantic relationship issues with parents and adolescents with ASD. Professionals should do this actively and early. Thus, this subject should also get attention in professional training.

Offering early and comprehensive sexuality education

CSE for children and adolescents with ASD starting in early development (see for example SIECUS, 2004) is necessary and should be part of standard school curriculum through all grades. If schools do not offer CSE, parents should look for alternatives (e.g. courses or individual training by another professional). This CSE should be attuned to the social and communicative characteristics of people with ASD, e.g. by using concrete language and information. CSE programmes for adolescents and adults with ASD have been published (e.g. Dekker, van der Vegt, et al., 2015; Hénault, 2005). Based on this thesis, some issues deserve additional attention. For instance, CSE should mention that not all boys with ASD have solo and partnered sexual interest and experiences. Examples of different ways to enjoy sexuality, other than the hetero-normative (i.e. only having sex in long-lasting heterosexual relationship) also deserve attention. Support and information to understand sexual explicit materials and sexuality related information on the internet and a list of reliable websites (information, reliable online chats, dating possibilities) relating to sexuality should be provided and discussed. Boys should be encouraged to discuss questions or frustrations pertaining to sexuality and relationships with reliable adults and peers. The qualitative study indicated that peers are a source of sexuality related information, indicating, to our opinion, the added value of guided discussion of sexuality issues in group, as a part of sexuality education.

Discussing individual experiences of sexuality and relationships with boys with ASD

Individual and open communication about relationships and sexuality, in an active and open manner, is advisable in order to understand how boys with ASD think and feel about sexuality, and to detect possible issues or worries they experience. We suggest making sure that there is a reliable adult (parent, professional or other) in the surrounding of every adolescent with ASD who regularly initiates a discussion on how the adolescent deals with sexuality and relationships issues. An open discussion with the adolescents demands clear preconditions, good conversation skills, and an open attitude towards sexuality. Based on our clinical experience, it is advisable to check the meaning (what do you mean, what does the

adolescent means or understands) of all sexuality related terminology. Adequate information should be offered after discussing sexuality related topics. Limit and norm setting might impede the adolescent to discuss questions pertaining to atypical interests and experiences. In the assessment of sexual inappropriate behaviours, the experience and sense making of the adolescent or adult with ASD should get attention. In those cases, involvement of a professional, experienced in discussing and assessing sexuality in individuals with ASD is advisable. Also then, the focus should lie on detecting ways to stimulate and support the development towards sexual health. In Addendum 1, some preconditions to discuss sexuality issues in clinical practice can be found, as well as proposed exemplary questions to guide the conversation.

CONCLUSION

Sexuality is a normative part of adolescent development in high-functioning boys with ASD, as it is for their peers in the general population. The majority of boys had common and age-appropriate solo and partnered sexual experiences, and only few reported coercion or problematic sexual behaviours. This thesis found that only a small group of boys with ASD did not, or only at later age, gain partnered experience. Although some boys in this thesis had no partnered or even any sexual experience, they reflected about themselves in relation to sexuality and romantic relationships. The personal accounts revealed that sexual experiences could be positive and age-appropriate, however in some boys atypical, and sometimes inappropriate. Challenges related to developing sexual identity and relationships also appeared. Although the stories of the participants revealed the complexity of sexuality development, this thesis did not support a predominant problematising view on ASD and sexuality. Communicating about sexuality on a personal level seemed challenging for a lot of adolescents, parents, and caregivers. The underestimation of sexual experience by parents might add to the hesitation to discuss the topic. It is important that parents and professionals are aware of the normativity of sexuality in adolescent boys with ASD, that they offer them comprehensive sexuality education, and individual communication to support healthy sexual development.

ADDENDUM 1

Below you will find a possible introduction and exemplary questions to discuss and explore sexuality and dating in adolescents with ASD. Before discussing sexuality some consideration about the preconditions to this are important.

The conditions for discussing sexuality issues should be clear for you and the adolescent: why do you want to discuss this (support/assessment/control)? What happens with the information? What if it does not feel right for the adolescent? Does the adolescent know who he can contact if he has any further questions or issues? Does the adolescent understand that this discussion is different from the way he can talk about sexuality in other situations (e.g. in public)?

Always check the terms you use: what do they mean for the adolescent?

A possible introduction to discuss sexuality can be as follows:
Sexuality and dating are part of our life. That does not mean that everybody has a partner or has experience with sex. For some boys, learning about sex is obvious, while it seems more challenging to others. Sexuality is a part of our life so we need to deal with it in a good and enjoyable way. Since we discuss how you feel, sleep, and eat, I think we also can discuss sexuality. However, we learn we should keep this in private and that is also alright. You cannot discuss this with everybody. With who is it OK for you to discuss this with? If you have questions, who can you go to?

I want to discuss how you feel about dating and about sexuality. If you have questions or remarks about my questions, please feel free to react! You can let me know if you do not want to discuss some issues.

- How do you think about sexuality in boys/girls of your age? Is it OK?
- Have you ever been in love? How did you know? Have you ever had a girl- or boyfriend? Do you know whether you like girls, boys, or both? Would you want to have a relationship? Why? Why not?
- Most adolescents feel sexual arousal, however differences exist. Do you get sexually aroused sometimes? How do you know? Do you know what it means to have an orgasm? Did you experience it yourself? Did you try masturbation? How do you feel about it?
- Other things such as a specific feeling, smell, or specific feature sexually arouse some people. Did you ever experience this? How do you feel about this?
- Did you ever do sexual things with someone else? Can you tell me about it? How did you feel about it? Would you want to try this? How do you feel about the fact that you did not do this yet?

- Where did you learn about sexuality and dating? Parents? Other boys or girls? Internet? Do you discuss sexuality and dating with anyone?
- There is a lot of porn on the internet. Do you watch porn? What kind do you like? Some people spend a lot of time with it. How do you feel about that? Do you do other sexually related things on the internet (chatting, dating, posting pictures, …).
- Do you ever worry about sexuality or relationships? Can you tell me about it?
- Some people do get in trouble, sometimes by accident. I think it's important to discuss it and to make sure you deal with sexuality in a way that is OK for you and for the other. Do you think you ever did inappropriate sexual things? Can you tell me about it?

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NEDERLANDSE SAMENVATTING

INTRODUCTIE

Seksualiteit is een belangrijk onderdeel van de ontwikkeling tijdens de adolescentie (Fortenberry, 2013b; Moore & Rosenthal, 2006). Er is in toenemende mate aandacht voor seksualiteit als een positief en normaal onderdeel van een gezonde ontwikkeling (Tolman & McClelland, 2011) maar lange tijd hebben onderzoekers en beleidsmakers zich vooral gericht op risicofactoren en negatieve aspecten (bijvoorbeeld tienerzwangerschappen, ziektes, grensoverschrijdend gedrag) van seksualiteit bij adolescenten. Twee termen, die ook in dit proefschrift centraal staan, weerspiegelen deze meer positieve visie op seksualiteit: normativiteit en seksuele gezondheid. Als men zegt dat seks een normatief onderdeel is van de ontwikkeling in de adolescentie dan betekent dit dat men verwacht dat jongeren bezig zijn met seks en dat dit een positief onderdeel uitmaakt van hun ontwikkeling (Tolman & McClelland, 2011). De Wereldgezondheidsorganisatie (WHO, 2006) promoot seksuele gezondheid, omschreven als welbevinden ten aanzien van seksualiteit; dat betekent niet enkel de afwezigheid van klachten of problemen maar ook een positieve houding ten aanzien van seksualiteit en relaties, en de mogelijkheid om dit op een veilige en positieve manier te ervaren.

Autisme Spectrum Stoornis (ASS) is een ontwikkelingsstoornis die volgens huidige schattingen voorkomt bij 1 op 152 mensen. De kenmerkende eigenschappen van ASS zijn beperkingen op vlak van sociale interactie, communicatie, en stereotype, repetitieve interesses en gedragingen, die al van op jonge leeftijd aanwezig zijn (APA, 2000). ASS gaat bij jongeren en volwassenen met ASS vaak samen met een cognitieve beperking, andere psychiatrische klachten en epilepsie (Levy et al., 2009). Er is geen eenduidige oorzaak van ASS gekend. De huidige wetenschappelijke kennis wijst op de belangrijke rol van genetische factoren in interactie met omgevingskenmerken (Rutter & Thapar, 2014). In de jaren 40 van de 20ste eeuw waren Hans Asperger en Leo Kanner bij de eersten om over kinderen en jongeren met deze kenmerken te publiceren en sinds 1980 is deze ontwikkelingsstoornis opgenomen in de Diagnostic and Statistic Manual (DSM).

In de populaire en wetenschappelijke literatuur met betrekking tot ASS is er tot op heden relatief weinig aandacht geweest voor seksualiteit. In de jaren ’80 van de vorige eeuw bestond nog discussie of seksualiteit wel een relevant thema was voor mensen met ASS (zie bijvoorbeeld Torisky & Torisky, 1985). In de daaropvolgende jaren was er vooral aandacht voor ongepast gedrag (bijvoorbeeld masturberen in het openbaar), opvallende interessepatronen (zoals fetisjismen), en moeilijkheden om een partner te vinden (Haracopos & Pedersen, n.d.; Hellemans, Colson, Verbraeken, Vermeiren, & Deboutte, 2007). Pas recent is er meer wetenschappelijke aandacht voor seksueel welbevinden, plezier en tevredenheid bij mensen met ASS zonder cognitieve beperking (Byers et al., 2013, 2012; Byers & Nichols, 2014; Gilmour et al., 2012). Ondanks de beschrijvingen van opvallend seksueel gedrag is

het onderzoek naar de seksuele ontwikkeling van jongeren en volwassenen met autisme nog zeer beperkt.

Het doel van dit proefschrift was om inzicht te verwerven in de seksuele ontwikkeling van adolescente jongeren zonder cognitieve beperking (totaal intelligentie quotient >70 (Bölte, 2014)). Het gegeven dat ASS twee tot vier keer meer bij jongens voorkomt dan bij meisjes (Levy et al., 2009) en dat de seksuele ontwikkeling van jongens en meisjes verschilt, leidde tot de keuze om dit onderzoek enkel op jongens te richten

OPZET VAN HET ONDERZOEK

Om inzicht te verwerven in de seksuele ontwikkeling van jongens met ASS zijn kwantitatieve en kwalitatieve onderzoeksmethoden (Creswell & Plano Clark, 2011) gecombineerd. De verwachting was dat een combinatie van beide benaderingen meer inzicht zou bieden in hoe jongens met autisme met seksualiteit omgaan. Het onderzoek bestond uit vier onderdelen: (1) een kritisch overzicht van het wetenschappelijk onderzoek over autisme en seksualiteit, (2) een vergelijking van de seksuele ervaring in een groep adolescente jongens met ASS met die van leeftijdsgenoten uit de algemene populatie, (3) de vergelijking van rapportage door ouders en hun zonen over de seksuele ervaring van de jongens met autisme, en (4) een studie over hoe jongens met autisme hun seksualiteit ervaren.

DEELNEMERS

Bij de start van het onderzoek in 2012 is een groep van 50 Nederlandse en Vlaamse jongens verzameld bij wie eerder een autistische stoornis of stoornis van Asperger (APA, 2000) was vastgesteld door een multidisciplinair team in de geestelijke gezondheidszorg. De deelnemende jongens waren tussen 15 en 18 jaar bij aanvang van het onderzoek en scoorden beneden gemiddeld of hoger (Totaal Intelligentie Quotiënt hoger dan 70) op een standaard intelligentietest (zoals de WISC-III). De deelnemers mochten geen psychotische kenmerken vertonen, op het moment van het onderzoek. De autismekenmerken (ADOS (Lord et al., 2012), ADI-R (Rutter et al., 2003)), intelligentie en de achtergrond van de deelnemers werden in kaart gebracht. De ouders van 43 van de deelnemende jongens waren bereid om een vragenlijst in te vullen over de seksuele ervaring van hun zoon. Drieënveertig jongens gaven aan dat ze opnieuw benaderd mochten worden voor onderzoek, waarvan er uiteindelijk 30 bereid waren om deel te nemen aan follow-up onderzoek in 2014. Bij acht van deze jongens werd daarnaast een interview afgenomen.

De controlegroepen bestonden uit jongens uit de Nederlandse bevolking die deelnamen aan het Seks onder je 25ste II onderzoek (de Graaf et al., 2012) met vergelijkbare culturele achtergrond, opleidingsniveau, leeftijd en regio. De onderzoekers van het SO 25II-onderzoek (De Graaf et al., 2012) waren zo vriendelijk om deze data ter beschikking te stellen

SAMENVATTING VAN DE BELANGRIJKSTE BEVINDINGEN

Hoofdstuk 1 biedt een kritisch overzicht van de wetenschappelijke publicaties over seksualiteit bij mensen met autisme in de periode tussen 1980 en 2012. Screening van verschillende wetenschappelijke databases leverde 55 Engelstalige artikelen op. De helft (29) van deze publicaties zijn casestudies, overwegend over jongeren of volwassenen met ASS die opvallend seksueel gedrag vertoonden. De overige 26 studies bieden inzicht in diverse aspecten van seksualiteit bij jongeren en volwassenen met ASS, maar worden gekenmerkt door verschillende methodologische beperkingen. Deze studies zijn namelijk gebaseerd op kleine en vaak heterogene onderzoeksgroepen (beide geslachten, verschillend niveau van functioneren, verschillende leeftijden) en op verschillende onderzoeksmethoden (verschillende vragenlijsten, instrumenten en informanten). Dit maakt het moeilijk om de resultaten te generaliseren.

De resultaten van de onderzoeken werden samengebracht volgens drie thema's: seksueel gedrag, individualiteit en socialisatie, in navolging van Tolman & McClelland (2011). De meeste gegevens zijn beschikbaar over seksueel gedrag. Cijfers over masturbatie waren hoger voor mannen dan vrouwen, maar lagen algemeen gezien lager dan in de algemene populatie. Soms moest aan jongeren en volwassenen met ASS expliciet worden geleerd hoe te masturberen en tot een orgasme te komen. In het openbaar, overmatig of dwangmatig masturberen zijn ook beschreven in verschillende studies. Ongepaste seksuele gedragingen worden minder gevonden bij hoger functionerende jongeren en volwassenen. Verschillende bijzondere interesse- en opwindingspatronen zijn beschreven (zoals interesse in specifieke lichaamsdelen of prikkels), maar er is geen duidelijkheid over hoe vaak dit voorkomt bij mensen met autisme. Onderzoek naar partnergerichte ervaringen en interesses liet zien dat vooral hoger functionerende en sociaal meer vaardige jongeren en volwassenen met autisme hier interesse in of ervaring mee hebben. Algemeen gezien lijkt de ervaring met partnergerichte seks en relaties lager te zijn bij jongeren en volwassenen met ASS in vergelijking met de algemene bevolking. Ongepaste seksuele gedragingen (bijvoorbeeld stalking, iemand aanraken zonder toestemming) en opvallende verliefdheden (zoals op beroemdheden) zijn beschreven. Gegevens over het voorkomen van ongepaste of bijzondere gedragingen ontbreken tot op heden.

Er is minder onderzoek naar de seksuele individualiteit of sexual selfhood (Tolman & McClelland, 2011): hoe iemand denkt over zijn seksualiteit, zichzelf ziet als seksueel wezen, over zijn (gender)identiteit en hoe iemand zichzelf ziet in een relatie. De meeste deelnemers aan de onderzoeken hadden minstens enige seksuele interesse. De resultaten van een aantal studies suggereerden dat meer jongeren en volwassenen zich aangetrokken voelen tot iemand van hetzelfde geslacht. De meeste deelnemers hadden voldoende basiskennis over seksualiteit, maar deze kennis leek niet automatisch toegepast te worden in het dagelijkse leven. Studies over seksueel welbevinden waren niet eenduidig. Recent onderzoek liet wel zien dat beter functionerende volwassenen met autisme met of zonder een partner seksuele voldoening en welbevinden rapporteerden. Tenslotte besteedden verschillende publicaties aandacht aan genderdysphorie (spanning tussen het ervaren en biologische geslacht) en genderidentiteitsmoeilijkheden, maar er zijn nog geen eenduidige cijfers over het voorkomen hiervan bij jongeren en volwassenen met ASS.

Onderzoek naar seksuele socialisatie, over hoe jongeren leren over en gevormd worden omtrent seksualiteit, richtte zich overwegend op de ervaringen van ouders en professionals. Ouders zijn voor veel jongvolwassenen met ASS belangrijke steunfiguren. Ze rapporteerden in verschillende onderzoeken hun zorg over de seksualiteit van hun kinderen, onder meer over hoe andere mensen het seksuele gedrag van hun kinderen zullen interpreteren, en over misbruik van en door jongeren en volwassenen met ASS. Overtuigingen van ouders over hoe hun kinderen met seksualiteit omgaan of zouden kunnen gaan, over de mogelijke invloed van voorlichting en over hun verantwoordelijkheid daarin, beïnvloedde de mate waarin deze ouders seksuele voorlichting boden. Ouders gaven echter herhaaldelijk aan dat ze seksuele opvoeding wilden bieden, maar vroegen handvatten en ondersteuning om dit goed te doen. Zij voelden zich hierin vaak niet ondersteund door professionals. Sommige leerkrachten en hulpverleners rapporteerden wel een open houding ten opzichte van seksualiteit en relaties bij mensen met ASS, maar dat bleek niet altijd uit hun handelen. Professionals leken ook weinig scholing te hebben gehad om met dit thema aan de slag te gaan. Onderzoek naar het effect van seksuele opvoeding en invloed van andere bronnen van informatie over seksualiteit, zoals leeftijdsgenoten, het internet en andere media is zeer beperkt. Verder suggereerde onderzoek dat leeftijdsgenoten minder van invloed zijn, omdat jongeren met ASS minder vriendschappen opbouwen. Twee publicaties illustreerden dat een hoog aantal (jong)volwassenen met ASS slachtoffer was van misbruik en vonden een samenhang tussen dit misbruik en hun seksuele gedrag op latere leeftijd.

Deze literatuurstudie laat zien dat het onderzoek naar dit thema nog beperkt en divers is. Er is nog weinig inzicht in de seksuele ontwikkeling van jongeren met ASS hoewel dit relevant is voor het ontwikkelen van een goed vormings-, ondersteunings- en behandelaanbod.

Hoofdstuk 2 beschrijft de seksuele en relationele ervaring en attitudes van een groep jongens met ASS (n=50) van 15 tot 18 jaar oud, in vergelijking met die van jongens uit de algemene Nederlandse bevolking (n=90). Alle jongens hebben de vragenlijst uit het 'Seks onder je 25ste II' onderzoek ingevuld (de Graaf et al., 2012): een vragenlijst over een breed scala aan seksualiteit gerelateerde thema's. De jongens met autisme bleken weinig tot niet te verschillen van de jongens in de controlegroep wat betreft hun ervaring met solo en partnergerichte seksuele handelingen. Bijna alle jongens, met en zonder ASS, waren al wel eens verliefd en hadden ervaring met masturbatie. De meerderheid van de jongens had ook al eens een relatie. De helft van de jongens had al eens getongzoend en ongeveer een kwart van hen had meer intieme seksuele ervaring met een partner. De gemiddelde leeftijd waarop de jongens ervaring opdeden met relaties en seksualiteit verschilde niet. De meeste jongens, met en zonder ASS, voelden zich aangetrokken tot jongeren van het andere geslacht. Eén op vijf jongens met ASS had ervaring met of interesse in vrijen met een andere jongen. De jongens in dit onderzoek hadden overwegend permissieve en positieve opvattingen over seksualiteit. Enkel waren er meer jongens met ASS die accepterend waren ten opzichte van homoseksualiteit dan in de controlegroep. De meerderheid van de jongens was al in aanraking gekomen met seksueel expliciet materiaal, voornamelijk porno op het internet. Ongeveer de helft van de jongens met autisme gebruikte het internet ook op andere manieren om met seksualiteit bezig te zijn (zoals chatten of foto's versturen). Het aantal jongens dat aangaf gedwongen te zijn of anderen gedwongen te hebben tot seksuele handelingen was in beide groepen zeer klein.

De hogere percentages met betrekking tot seksuele ervaringen in deze studie, vergeleken met eerder onderzoek, zijn mogelijk te verklaren door het gebruik van zelfrapportage, in de plaats van rapportage door ouders of verzorgers. Deze studie onderbouwt dat seksualiteit een normatief onderdeel is van de ontwikkeling van jongens met ASS zonder cognitieve beperking. De gegevens uit het onderzoek bieden echter enkel informatie over of jongeren ervaring hebben met de meest voorkomende seksuele gedragingen, en niet over de aard, het verloop en kwaliteit van die ervaringen. Gegevens over de frequentie, beleving, context en het verloop van die ervaringen ontbreken. Eerder onderzoek, in de algemene bevolking, liet zien dat uitgebreide relationele en seksuele vorming aan jongeren resulteert in een gezondere manier om met seks om te gaan. Ook bij jongeren met ASS neemt men aan dat relationele en seksuele vorming een belangrijke rol kan spelen in een gezonde seksuele ontwikkeling. Dit onderzoek onderbouwt het belang van aandacht voor seksualiteit en relaties in de opvoeding van en het onderwijs en hulpverlening aan deze jongeren en hun context.

In *Hoofdstuk 3* zijn de zelf- en ouderrapportage (n=43 ouder – adolescent paren) over de seksuele ervaring van de adolescent vergeleken. Het doel was om na te gaan in welke mate ouders op de hoogte zijn van de seksuele ervaring van hun zonen met ASS. Algemeen

gezien onderschatten ouders de seksuele ervaring van de jongens. Dit viel het duidelijkste op met betrekking tot masturberen: bijna alle jongens gaven aan dit wel eens te hebben gedaan, terwijl maar ongeveer de helft van de ouders aangaven dat, volgens hen, dit zo was. De cijfers over de partnergerichte ervaringen, waar nog minder jongens op die leeftijd ervaring mee hadden, liepen minder ver uit elkaar. Drie kwart van de ouders was er wel van op de hoogte dat hun zoon een relatie had. De onderschatting door ouders kan verklaard worden doordat de jongens adequaat omgingen met seksualiteit (bijvoorbeeld door te letten op privacy). Anderzijds kan dit ook wijzen op een beperkte communicatie tussen ouders en kinderen over seksualiteit. Eerder onderzoek vond dat ouders pas in gesprek gaan over seks en relaties op het moment dat zij vermoeden dat dit relevant is voor hun kinderen. De onderschatting door ouders van de seksuele ervaring van hun zonen kan dus impliceren dat ouders te weinig of pas laat in gesprek gaan over seks. Het lijkt dus belangrijk om ouders te informeren over de seksuele ontwikkeling van jongens met ASS. Tenslotte kan op basis van deze studie worden verondersteld dat eerdere onderzoeken die zijn gebaseerd op rapportage door ouders en derden een onderschatting weergeven van de seksuele ervaring van jongeren en volwassenen met ASS.

In *Hoofdstuk 4* is de seksuele ervaring van de jongens met ASS (n=30 van de oorspronkelijke 50 deelnemers) opnieuw in kaart gebracht en vergeleken met een controlegroep (n=60) twee jaar na de eerste meting. De deelnemers waren tussen 16 en 20 jaar op het moment van deze follow-up studie. Minder jongens met autisme (70%) hadden op dat moment seksuele ervaring met een partner vergeleken met de jongens in de controlegroep (91%). De verschillen waren het duidelijkst met betrekking tot ervaring met tongzoenen en strelen boven de kleren: minder jongens met autisme hadden hier ervaring mee, vergeleken met de controlegroep. Iets meer dan de helft van de jongens met autisme had ervaring met meer intieme seksuele handelingen en geslachtsgemeenschap met een partner. De meeste jongens, ook in de groep met ASS, bouwen stap voor stap seksuele ervaring op, startend met minder intieme handelingen (zoenen, strelen) en daarna meer intieme (naakt strelen, geslachtgemeenschap). De resultaten in deze studie suggereren dat een kleine groep jongens met ASS niet de stap naar partnergerichte ervaringen zette en dat deze groep groter is dan bij jongens in de algemene Nederlandse bevolking. Mogelijk is dit de groep die pas op latere leeftijd ervaring met een partner opdoet, die Byers, Nichols, & Voyer (2013) vonden in hun onderzoek bij volwassenen met ASS. Op basis van deze bevindingen worden verschillende ontwikkelingstrajecten gesuggereerd: een eerste en grootste groep (70%) die op vergelijkbare leeftijd als andere jongens gaat experimenteren met seks en ervaring opdoet met een partner, een tweede kleinere groep (25%) die wel bezig is met seks maar niet experimenteert met een partner, en een derde, kleine (5%) groep die weinig seksuele interesse ervaart op deze leeftijd. Aanvullende informatie over de partnergerichte seksuele ervaringen liet zien dat

jongens, met of zonder ASS, seksuele ervaring opdoen in verschillende soorten relaties. De jongens met ASS voelden zich meestal wel klaar om seks te hebben, maar voor verschillende onder hen kwam de eerste keer toch onverwacht. Een aantal jongens gebruikte daarbij geen condoom. Verschillende jongens rapporteerden nadien ook enige spijt over deze ervaring. Verder onderzoek is nodig om na te gaan hoe jongens met autisme de beslissing nemen om seksueel contact aan te gaan, en op wat de invloed van seksuele en relationele ervaringen tijdens de adolescentie is op de verdere ontwikkeling en seksuele gezondheid. De resultaten van deze studie suggereren dat het zinvol is om relationele en seksuele vaardigheidstraining af te stemmen op de ervaring van de jongere: bij jongens die relaties aangaan en seksueel contact hebben met een partner is aandacht voor (seksuele) interactie (hoe afstemmen, wat kan je verwachten, wat doen anderen, hoe doe je het veilig) met een partner zinvol, andere jongeren lijken meer nood te hebben aan ondersteuning om contact aan te gaan met een potentiële partner en bij een klein aantal jongens lijkt het goed om de beperkte interesse in seksualiteit en relaties te kaderen en normaliseren.

In *Hoofdstuk 5* zijn de resultaten van de Interpretative Phenomenological Analysis (IPA) beschreven van interviews die zijn afgenomen bij acht deelnemers uit de oorspronkelijke onderzoeksgroep. Deze kwalitatieve onderzoeksmethodologie is ontwikkeld om door kwalitatieve analyse van persoonlijke getuigenissen, in dit geval interviews, een onderbouwd idee te vormen over hoe individuen een fenomeen ervaren en er betekenis aan geven. De jongens beschreven uiteenlopende seksuele en relationele ervaringen, gaande van een jongen die geen opwinding ervoer tot een jongen die zijn opwinding als onbeheersbaar beschreef, van vroeg experimenteren met vriendinnetjes tot anderen dwingen tot seksuele handelingen, van experimenteren met zoenen en vrijen tot het uitproberen van BDSM (Bondage/Discipline, Dominance/Submission, Sadism/Masochism). De jongens beschreven hoe ze leerden over hun seksualiteit op basis van de signalen van hun lichaam, het interpreteren van wat ouders, leerkrachten, leeftijdsgenoten al dan niet doen en zeggen, van informatie op het internet, en uit de ervaringen met een partner. Niet alle jongens voelden zich competent als partner, in samenhang met hoe ze zichzelf inschatten op sociaal en communicatief vlak, en met hun ervaringen met potentiële partners. Al de jongens konden vertellen over hoe ze hun seksualiteit ervoeren, ook diegene met beperkte ervaring, op basis van hun beleving van lichamelijke opwinding, de boodschappen over seksualiteit uit de omgeving, en de ervaringen met potentiële partners. Het bespreken van hun persoonlijke beleving en ervaringen bleek niet vanzelfsprekend en was iets wat weinig onder hen eerder hadden gedaan.

De complexiteit van de seksuele ontwikkeling bleek in deze studie: je lichamelijke reacties en aantrekking herkennen, een idee vormen van wat je leuk vindt en wilt, begrijpen wat gepast en normaal is, contact leggen met een partner en onderhandelen of intimiteit en

seksualiteit zijn enkele van de aspecten die aan bod kwamen. De verhalen van de jongens illustreerden hoe autismekenmerken dit, bij sommigen, nog ingewikkelder maken. Het ondersteunen van de seksuele ontwikkeling dient dan ook verder te gaan dan het bieden van kennis en informatie. Communicatie over persoonlijke ervaringen en beleving lijken belangrijk om samen met jongeren te zoeken hoe zij seksualiteit op een leuke en gepaste manier kunnen integreren in hun dagelijkse functioneren.

DISCUSSIE

Zijn jongens met ASS wel bezig met seksualiteit?

De resultaten van dit onderzoek nuanceren de eerdere veronderstellingen dat jongeren en volwassenen met autisme geen of minder interesse hebben in seks, dat ze minder ervaring hebben en pas op latere leeftijd seksueel actief zouden worden. De meeste jongens met autisme in deze thesis, ongeveer 70%, waren geïnteresseerd in seks, startten vroeg in de tienerjaren met masturberen, en deden stapsgewijs ervaring op met partners op vergelijkbare leeftijd als jongens in de algemene populatie. Een tweede groep, ongeveer een kwart van de jongens, was geïnteresseerd in seks, had ervaring met masturbatie sinds het begin van de tienerjaren, maar wachtte langer dan leeftijdsgenoten om met een partner te experimenteren. Persoonlijke (bv. onzekerheid om een partner te benaderen, nog geen behoefte aan een partner) en omgevings- (bv. weinig gelegenheid ervaren om een potentiële partner te ontmoeten) kenmerken kunnen hierin een rol spelen. Een derde, zeer kleine, groep bestond uit jongens die geen opwinding of seksuele interesse ervaren op deze leeftijd, en weinig interesse hadden in het aangaan van een relatie. Deze groepen zijn mogelijk niet anders dan in de algemene populatie. In dit onderzoek was de tweede groep echter groter bij de jongens met autisme in vergelijking met de jongens uit de algemene populatie. De jongens met autisme bleken wel na te denken over seks en relaties, los van hun ervaring. Seks en relaties zijn dus onderdeel van de ontwikkeling van adolescente jongens met ASS.

Deze bevindingen sluiten aan bij resultaten van eerder onderzoek bij volwassenen met autisme die geïntegreerd in de maatschappij functioneren (onder meer Gilmour et al., 2012), maar spreken bevindingen in andere groepen tegen (bijvoorbeeld Hellemans et al., 2007; Hellemans, Roeyers, Leplae, Dewaele, & Deboutte, 2010; Ousley & Mesibov, 1991). Deze studies kunnen echter niet zomaar worden vergeleken omdat de kenmerken van de onderzoeksgroepen erg verschilden (bv. de jongeren in de studie van Hellemans et al. (2007) verbleven in een leefgroep). Bij het interpreteren van de resultaten is het dan ook belangrijk om de kenmerken van de jongens met ASS in deze studie in gedachten te houden: de

bevindingen zijn niet zonder meer generaliseerbaar naar andere jongeren met autisme. Verschillende studies zijn ook gebaseerd op informatie van ouders of derden, en niet op zelfrapportage. Een substantieel deel van de ouders in deze thesis onderschatten echter de seksuele ervaring van hun zoon. Deze verschillende aspecten kunnen een verklaring bieden voor het verschil tussen de resultaten in dit proefschrift en die van bovenstaande studies. Deze thesis bevestigt dat het voor ouders en professionals belangrijk is om er bewust van te zijn dat seksualiteit onderdeel is van de ontwikkeling tijdens de adolescentie.

Wat is dan een normale seksuele ontwikkeling bij jongens met autisme?

Het aantal jongens met autisme dat, in deze thesis, ervaring heeft met de meest voorkomende seksuele gedragingen verschilde weinig tot niet van dat bij leeftijdsgenoten. Bijna alle jongens met autisme in dit onderzoek hadden wel eens gemasturbeerd en een orgasme ervaren, gemiddeld op 13-jarige leeftijd. De meerderheid is wel eens verliefd geweest en heeft een relatie gehad. Rond hun 15de had een derde van de jongens al enige ervaring met een partner, en een kwart van de jongens met autisme heeft dan al eens geslachtsgemeenschap gehad. Tegen het einde van hun tienerjaren had de helft van de jongens in dit onderzoek hier ervaring mee. Uit de verkenning van de seksuele ervaringen van de jongeren met autisme bleek verder dat er heel wat variatie bestond in het type relatie waarin jongens seksuele ervaring opdoen (bijvoorbeeld met een vakantieliefde, met een gewone vriendin, tegen betaling of binnen een relatie), en in de aard van hun seksuele ervaringen (zoals experimenteren met BDSM, anale seks). In tegenstelling tot eerdere onderzoeken (onder meer Gilmour et al., 2012; Hellemans et al., 2007), bleek uit dit onderzoek niet dat een hoger aantal jongens met autisme interesse of ervaring hebben in seksueel contact of verliefdheid op iemand van hetzelfde geslacht.

Seksualiteit lijkt dus een normatief onderdeel van de ontwikkeling van de jongens met autisme in deze thesis: deze adolescenten zijn bezig met seks en relaties, net zoals hun leeftijdsgenoten. Dit houdt in dat we kunnen verwachten dat normaalbegaafde jongens met autisme ervaring opdoen met solo- en partnergerichte seksuele handelingen. Normativiteit betekent niet dat alle jongens met autisme moeten masturberen of seks met een partner moeten hebben: sommige jongeren doen dit niet, net zoals jongeren zonder autisme. Het kan bijvoorbeeld weinig aantrekkelijk zijn om een relatie te hebben en daarbij je persoonlijke ruimte te moeten delen met een partner. Vertrekkende van de definitie van seksuele gezondheid hebben jongeren idealiter een positieve attitude ten aanzien van seksualiteit en voelen ze zich goed bij de manier waarop zij hun seksualiteit ervaren. Jongeren die verlangen naar een relatie en seks zouden dus in staat moeten zijn om dit te ervaren op een veilige en leuke manier, en afgestemd op hun partner. Jongeren zonder interesse zouden moeten ervaren dat dit ook goed is, maar ook bij hen is voldoende kennis en een open houding (in

tegenstelling tot angst of vermijding) ten aanzien van het thema belangrijk. Deze thesis suggereert dat dit niet steeds het geval is: sommige jongeren voelden zich geremd om een partner te vinden, ervoeren dat ze niet voldeden aan de verwachtingen van hun omgeving, of waren over grenzen van anderen gegaan. De definitie van seksuele gezondheid (WHO, 2006) biedt een kader om met jongeren met autisme en hun ouders stil te staan bij hoe ze seksualiteit en relaties ervaren en er mee omgaan. Op basis daarvan kunnen we met hen bedenken wat zij nodig hebben (zoals de vaardigheden om een partner te benaderen, maar evenzeer de geruststelling dat niet iedereen een relatie hoeft te hebben of opgewonden raakt van dezelfde prikkels) om evenwichtig te ontwikkelen op gebied van seks en relaties.

Is bezorgdheid over seksualiteit bij jongens met autisme nodig?

De resultaten in dit proefschrift weerleggen een eenzijdig problematiserende benadering van seksualiteit bij jongens met autisme. De meeste jongens met autisme rapporteerden doorsnee seksuele overtuigingen en ervaringen, en stelden zich eerder permissief en positief op ten opzichte van seksualiteit. Ze bleken zelfs wel wat toleranter ten opzichte van homoseksualiteit. Slechts een zeer klein aantal jongens met autisme rapporteerde dat ze wel eens iemand hadden gedwongen of dat ze zelf ooit gedwongen werden tot seksuele handelingen. Toch beschreven een aantal jongens in de kwalitatieve studie wat bijzondere, soms ongepaste, seksuele ervaringen. De analyse van de interviews illustreerde dat de seksuele ervaring van de jongens kon verwijzen naar een breed palet aan seksuele gedragingen: vaak gepast en vergelijkbaar met leeftijdsgenoten, soms wat bijzonder (zoals BDSM op jonge leeftijd) en, uitzonderlijk, ongepast (bijvoorbeeld andere dwingen). Een aantal van deze jongens ervaarden weinig houvast bij het leren omgaan met seks en relaties: het is een wat eenzame zoektocht in het leren begrijpen van je lichaam en gevoelens, in het begrijpen van normen en verwachtingen, in het vinden van en het afstemmen op een partner. Verschillende jongens beschreven dat ze opwinding spontaan gingen ervaren en herkennen, en zelf uitvonden hoe ze tot een orgasme konden komen. Uit eerder onderzoek (Hellemans et al., 2007) en deze thesis bleek echter dat dit geen vanzelfsprekendheid is voor alle jongeren. Ook wat betreft partnergerichte ervaringen is aandacht nodig voor de mate waarin jongeren voorbereid zijn op hun eerste keer, op het gebruik van voorbehoedsmiddelen, en voor welke ideeën zij hebben over seksualiteit. Mogelijk kunnen steun en informatie een gezonde seksuele ontwikkeling van jongens met autisme stimuleren. Afhankelijk van de ervaring en interesse van een jongere, kunnen andere aandachtspunten belangrijk zijn (zoals aandacht voor het afstemmen op een partner bij jongeren die actief op zoek gaan naar een relatie versus aandacht voor hoe iemand het ervaart om weinig interesse in relaties te hebben). Zorgwekkend seksueel gedrag kan, naast gelinkt te zijn met specifieke kenmerken van ASS (zoals sensorische overgevoeligheid of repetitiviteit),

samenhangen met een gebrek aan steun en informatie (ook beschreven als 'counterfeit deviance' (Hellemans et al., 2007)). De resultaten van dit onderzoek onderbouwen dus een genuanceerde benadering van dit thema: seksualiteit is een onderdeel van de ontwikkeling van adolescenten, waarbij de meeste jongens gewone ervaringen en ideeën hadden, maar sommige jongeren negatieve ervaringen oplopen of opvallende en soms afwijkende ideeën en gedragingen hebben. Op basis van deze studie is het echter nog steeds niet mogelijk om te stellen dat deze laatste groep groter is dan in de algemene bevolking.

Over de bloemetjes, bijtjes en porno: Leren over seksualiteit en relaties

De jongens in dit onderzoek leerden over seksualiteit uit allerlei bronnen: uit wat ouders al dan niet vertellen en doen, uit observatie, opmerkingen, en grappen van hun leeftijdsgenoten, uit voorlichting, via het internet en media, en uit ervaringen met leerkrachten, professionals en partners. De expliciete en impliciete boodschappen die de verschillende bronnen verschaften, leken daarbij vaak te verschillen en soms ook tegenstrijdig.

Ouders kwamen meer naar voren als diegene die grenzen stelden en normen communiceerden, eerder dan dat ze stimuleren om van seksualiteit te genieten. Ouders van jongeren met ASS in het onderzoek van Holmes & Himle (2014) gaven aan dat ze in gesprek gingen met hun kinderen over privacy, voorkomen van misbruik, hygiëne en relaties, terwijl seksualiteit en seksuele gezondheid in de brede zin minder aan bod kwamen. Eerder onderzoek bij ouders van kinderen met autisme (Ballan, 2012; Nichols & Blakeley-Smith, 2009) vond dat ouders pas gaan communiceren over seksualiteit wanneer ze denken dat dit relevant is voor hun kinderen. Een substantieel deel van de ouders in deze thesis onderschatte de seksuele ervaring van hun zonen. Deze onderschatting zou samen kunnen hangen met beperkte communicatie over seksualiteit, zoals bv. over masturbatie (Holmes & Himle, 2014). Ouders van jongens met autisme lijken hierin niet te verschillen van andere ouders (Diiorio et al., 2003; Frankel, 2002), maar gezien sommige jongeren met autisme niet spontaan een leuke manier vinden om te masturberen, zich soms pijn doen of frustratie ervaren (Haracopos & Pedersen, n.d.; Hellemans et al., 2007), en gezien masturbatie een belangrijke rol kan spelen bij het leren over opwinding en plezier (Fortenberry, 2013) is het wel aangewezen om hierover in gesprek te gaan. Het taboe om over persoonlijke ervaringen te praten, met de onderzoeker, maar ook met ouders, was zichtbaar in verschillende interviews. De openheid om over seks te praten verschilde tussen de gezinnen en leek niet noodzakelijk samen te hangen met openheid bij de jongeren. Jongens in dit onderzoek gaven zelf ook aan dat ze het gesprek met hun ouders over relaties en seks bevreemdend vonden en uit de weg gingen.

Leeftijdsgenoten en schoolgenoten leken in de verhalen van de jongens in dit onderzoek een belangrijke bron van informatie. Uit hun onderlinge communicatie, grappen

en plagen haalden jongens met autisme informatie over welk seksueel gedrag normaal is, in tegenstelling tot bevindingen van Stokes en collega's (2007). Een mogelijke verklaring voor dit verschil is dat deze laatste studie opnieuw was gebaseerd op rapportage door ouders.

Uit de interviews kwam het internet ook naar voor als een bron om informatie op te zoeken, om porno te vinden en om met anderen contact te hebben over seks en relaties. Bijna alle jongeren in de Westerse wereld hebben toegang tot het internet, vaak via verschillende apparaten (bv. computer, smartphone, tablet) (Livingstone et al., 2012). Het internet heeft dus aan belang gewonnen als een makkelijk toegankelijke bron voor informatie en seksueel expliciet materiaal. In onderzoek naar de invloed van het internet op de seksuele ontwikkeling van jongeren in de algemene bevolking vond men zowel positieve invloeden als risico's (Owens et al., 2012; Smith, 2012). De meerderheid van de jongens met (en zonder) autisme heeft wel eens porno op het internet bekeken. Jongens in dit onderzoek voelden zich bekwaam om de informatie hieruit goed te begrijpen en onderkennen dat porno eerder fictief dan realistisch is. Porno inspireerde sommige jongeren echter wel om hun seksuele repertoire te willen uitbreiden.

Jongens die ervaring hadden met een partner leerden ook in deze interactie over zichzelf, over seksueel gedrag en over hoe om te gaan met een partner. Uit de interviews kwam naar voren hoe jongens experimenteren, maar soms ook worstelen, met relaties en intimiteit. De sociale beperkingen die ASS kenmerken uiten zich waarschijnlijk ook in de interactiecompetentie in relaties (Vanwesenbeeck, Van Zessen, Ingham, Jaramazovic, & Stevens, 1999): de vaardigheden om eigen doelen en verlangens te realiseren en een positieve relatie te behouden. Mogelijk verklaart dit waarom de eerste keer seks onverwacht kwam voor een aantal jongeren en maakt dit sommige jongeren met autisme ook gevoeliger om wat meer atypische ervaringen op te doen (bv. door minder goed af te stemmen op een partner of door moeite om eigen grenzen aan te geven).

Op basis van de resultaten van dit onderzoek lijkt het leren over seksualiteit dus een complex proces, dat verder reikt dan het verwerven van kennis en leren uit seksuele voorlichting. Toch kan juist deze seksuele vaardigheidstraining en vorming helpend zijn om boodschappen over seksualiteit uit de omgeving goed te begrijpen, om te leren waar je informatie kunt vinden en om met deze complexiteit om te gaan.

Seksuele identiteit en ASS: Wie ben ik als het over seks en relaties gaat?

Uit de kwalitatieve studie werd duidelijk hoe de jongens met autisme zichzelf definieerden als een seksueel wezen (bv. 'ik ben er goed in' vs. 'ik voel me anders'), ook als ze geen of geen partnergerichte seksuele ervaring hadden. De manier waarop ze over zichzelf dachten als seksueel en relationeel wezen leek samen te hangen met hoe ze naar hun eigen vaardigheden en mogelijkheden keken (bv. 'Ik begrijp niet altijd goed wat anderen bedoelen'), hoe ze

lichamelijke gewaarwordingen interpreteerden (bv. 'ik voel me snel opgewonden'), en hoe ze hun solo- en partnergerichte ervaringen interpreteerden. De regels en normen die de jongeren afleiden uit de boodschappen en het gedrag van volwassenen en leeftijdsgenoten, uit informatie uit voorlichting en van op het internet vormen het kader om hun eigen ervaringen te evalueren en verwachtingen te vormen. Het idee dat ze over zichzelf als seksueel wezen en als partner vormden heeft mogelijk invloed op de intentie en manier waarop ze (al dan niet) partners benaderen en verder experimenteren. Deze processen werden eerder al beschreven in onderzoek bij adolescenten in de algemene populatie (Fortenberry, 2013; Tolman & McClelland, 2011) maar zijn nog weinig bestudeerd bij mensen met ASS. De meeste jongens met ASS in dit onderzoek dachten over seksualiteit als een normaal onderdeel van hun ontwikkeling en integreerden dit gepast in hun dagelijkse functioneren. Dat neemt niet weg dat een aantal jongens zichzelf beschreef als 'anders' of hun seksualiteit als vreemd en oncontroleerbaar ervoeren. Seksuele gezondheid verwijst naar een gevoel van welbevinden ten aanzien van seksualiteit (WHO, 2006). Er is dus aandacht nodig voor hoe jongeren en volwassenen met ASS naar zichzelf en hun seksualiteit kijken en hoe ze zich hier goed bij kunnen voelen. Hierover in gesprek gaan met jongeren is aangewezen maar waarschijnlijk complexer en persoonlijker dan het bieden van informatie over seksualiteit.

Once upon a time in the West

Bij het interpreteren van de resultaten in dit proefschrift is het belangrijk om rekening te houden met de tijd en plaats waarin dit onderzoek is uitgevoerd. Algemeen gezien hebben mensen in België en Nederland een meer liberale houding ten opzichte van seksualiteit (de Looze et al., 2014). Brede vorming rond relaties en seksualiteit is er onderdeel van de leerstof op school, in tegenstelling tot in andere landen. In grote delen van de Verenigde staten is bijvoorbeeld lang nadruk gelegd op onthouding en het voorkomen van seks voor het huwelijk (Kendall, 2014). De jongens in dit proefschrift hebben dus waarschijnlijk meer en bredere vorming rond relaties en seksualiteit gekregen dan jongeren in andere delen van de wereld.

EEN KRITISCHE NOOT EN SUGGESTIES VOOR TOEKOMSTIG ONDERZOEK

Een aantal kenmerken maakten deze studie vernieuwend en sterk. De onderzoeksgroep was relatief homogeen wat betreft diagnose, leeftijd en intelligentie, en vergelijking met een controlegroep was mogelijk. De jongeren werden ook rechtstreeks bevraagd en vergelijking met gegevens verstrekt door ouders was mogelijk. Verder bood het gebruik van verschillende methoden zowel inzicht op groepsniveau als in de individuele beleving.

Dat neemt niet weg dat er een aantal beperkingen zijn die moeten worden meegenomen bij het interpreteren van de resultaten. De kenmerken van de onderzoeksgroep beperken de generaliseerbaarheid (o.m. door selectiebias, door dat enkel hoog functionerende jongens deelnamen, door uitval bij de follow-up meting). Daarnaast biedt de vragenlijst beperkte informatie (enkel over het ooit ervaren van verschillende gedragingen en niet over de context en frequentie, en weinig informatie over atypische interesses en gedragingen). Tenslotte werden de jongeren slechts een beperkte tijd gevolgd, terwijl de seksuele ontwikkeling blijft doorlopen.

Op basis van de resultaten en de beperkingen van deze thesis is verder onderzoek wenselijk. Een aantal suggesties werden besproken, onder meer onderzoek naar de verdere seksuele en relationele ontwikkeling van jongeren met autisme die al dan niet op jongere leeftijd al ervaring hebben opgedaan met seks en relaties. Daarnaast is ook onderzoek naar seksualiteit bij meisjes en vrouwen met ASS wenselijk. Verder kan onderzoek naar hoe jongeren met ASS zich ontwikkelen die zich aangetrokken voelen tot jongeren van hetzelfde geslacht, die genderidentiteitsvragen ervaren of atypische seksuele interesses of opwindingspatronen hebben, inzicht bieden in welke ondersteuning helpend voor hen kan zijn. Dit geldt ook voor jongeren en volwassenen met ASS die ongepast of grensoverschrijdend seksueel gedrag stelden. Tenslotte zou het zinvol zijn om theoretische modellen en onderzoeksmethoden uit seksualiteitsonderzoek in de algemene populatie meer te integreren in het onderzoek bij mensen met autisme.

WAT BETEKENEN DE RESULTATEN VAN DEZE STUDIE VOOR DE DAGELIJKSE PRAKTIJK?

De resultaten in deze thesis tonen aan dat seksualiteit een normatief onderdeel is van de ontwikkeling van adolescenten met ASS. Gezien de complexiteit van dit ontwikkelingsgebied en om een gezonde seksuele ontwikkeling te stimuleren bij zoveel als mogelijk jongeren met ASS, zijn de volgende adviezen geformuleerd.

Ouders, jongeren en de professionals die ze begeleiden zouden op de hoogte moeten zijn van het gegeven dat seksualiteit een normatief onderdeel is van de ontwikkeling van adolescente jongens met ASS. Het verspreiden van informatie over seksualiteit bij jongeren met autisme via publicaties en websites, en het besteden van aandacht aan dit thema in de opleiding en training van professionals in het onderwijs en hulpverlening zou hiertoe kunnen bijdragen.

Het is zinvol om al vanaf jonge leeftijd brede relationele en seksuele vaardigheidstraining (RSV) te bieden aan kinderen, jongeren en later aan volwassenen met ASS. Ouders

dienen natuurlijk betrokken te zijn in de relationele en seksuele opvoeding door derden (leerkrachten, trainers, hulpverleners). Om goede voorlichting aan kinderen en jongeren met autisme te ondersteunen is het belangrijk om beschikbare (les)pakketten bekend maken (Dekker, Vegt, et al., 2015; Hénault, 2005) en ze te evalueren. Gezien het toenemende belang van het internet adviseren we om betrouwbare informatieve websites bekend te maken bij jongeren met ASS.

Het is belangrijk om met jongeren met ASS open in gesprek te gaan over hun seksuele ontwikkeling, om samen met hen stil te staan bij eventuele vragen, zorgen en moeilijkheden. We denken dat het belangrijk is dat er steeds aandacht is voor welke betrouwbare volwassene met kinderen en jongeren het gesprek over seksualiteit en relaties aangaat en onderhoudt. Ondersteuning en handvatten dienen ter beschikking te zijn om deze gesprekken aan te gaan. Tenslotte adviseren we sterk om een deskundige op vlak van seksualiteit en autisme te betrekken wanneer er zorgen zijn op vlak van seksualiteit bij een jongere of volwassene met ASS.

CONCLUSIE

Experimenteren met seksualiteit en relaties zijn een normatief onderdeel van de ontwikkeling van jongens met autisme, zoals dat ook geldt voor hun leeftijdsgenoten zonder ASS. De meerderheid van de jongens met ASS in deze thesis had actief geëxperimenteerd met de meest voorkomende seksuele gedragingen, zowel solo als met een partner. Een klein aantal jongens met ASS, maar meer dan in de algemene bevolking, leek niet of pas later ervaring op te doen met een partner. Ook deze jongens dachten over zichzelf en hun seksualiteit na. Slechts een zeer klein aantal jongens, met of zonder autisme, had iemand gedwongen tot seksuele handelingen. De persoonlijke verhalen van een aantal jongens illustreerden dat sommige jongens bijzondere, en soms grensoverschrijdende, seksuele ervaringen hadden, maar er is geen onderbouwing voor een eenzijdig problematiserende benadering van seksualiteit bij jongens met ASS. Jongens in deze thesis beschreven uitdagingen in het ontdekken en vormen van een seksuele identiteit en in de omgang met een partner. Ouders onderschatten de seksuele ervaring van adolescente jongens met ASS, wat mogelijk de mate waarin ze hierover in gesprek gaan met de jongens beïnvloedt. Het bleek echter ook dat het voor jongens met autisme, net zoals voor veel jongens zonder autisme, niet vanzelfsprekend is om over hun seksuele ervaringen in gesprek te gaan. Het belang van brede seksuele opvoeding is al aangetoond in de brede bevolking en is mogelijk nog belangrijker voor jongeren met autisme. Afhankelijk van hun ervaring zijn andere nadrukken in seksuele opvoeding en communicatie te overwegen: het benaderen en afstemmen op een partner,

om leren gaan met angst om iemand te benaderen of kaderen van (de afwezigheid) van ervaringen. Het is belangrijk dat ouders en professionals zich bewust zijn van seksualiteit als ontwikkelingstaak, dat ze brede seksuele en relationele vorming bieden en in gesprek gaan over seksualiteit en relaties, om jongens met ASS te ondersteunen om seksualiteit op een positieve manier te integreren in hun ontwikkeling en dagelijkse functioneren.

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Promoveren doe je niet alleen! Ik wil dus graag de mensen bedanken die hierin een rol hebben gehad.

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Jeroen

CURRICULUM VITAE

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Jeroen Dewinter was born on December 9th, 1977 in Berchem, Belgium. He completed secondary education (Sint-Annacollege, Antwerp) in 1995 and enrolled at KULeuven to study educational sciences (Pedagogische wetenschappen, afstudeerrichting orthopedagogiek). After graduation in 2000, he worked in residential youth care (vzw Haven, Hof Ter Heide and OOOC De Sluis). Between 2003 and 2006, he completed post-academic training in cognitive behavioural therapy at KULeuven. In the following year, he started to work at the University Centre for Child and Adolescent Psychiatry Antwerp, Belgium in a youth forensic psychiatry team and a youth psychiatric emergency team. In 2009, he started post-academic specialist training in Clinical Psychology in Eindhoven, the Netherlands (Rino Zuid). He completed this training while working at GGzE, centre for mental health care, in Eindhoven, the Netherlands. This research started as a part of this specialist training. The board of directors of GGzE granted him the opportunity to work on this PhD-study for 2 days during another two years at Tranzo, Scientific Center for Care and Welfare at Tilburg University. Since 2013, he coordinates an outpatient psychiatric team for emerging adults. During his PhD-training, he became certificated as ADOS and ADI-R trainer at Accare, the Netherlands.